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**Understanding low uptake of colorectal cancer screening in South East London  
exploration of demographic, psychological, social and cultural factors**

Dharni, Nimarta

*Awarding institution:*  
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**Title:** Understanding low uptake of colorectal cancer screening in South East London; exploration of demographic, psychological, social and cultural factors

**Author:** Nimarta Dharni

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**Understanding low uptake of colorectal cancer  
screening in South East London; exploration of  
demographic, psychological, social and cultural  
factors**

**Nimarta Dharni**

Thesis submitted for the degree of Doctor of Philosophy of the  
University of London

**King's College London**

**2013**

## **Abstract**

Colorectal Cancer (CRC) screening is offered in the UK to individuals aged 60-75 years through the faecal occult blood test (FOBT). Uptake of CRC screening is variable but particularly low in South East (SE) London, an area with high ethnic diversity and socio-economic deprivation. Reasons for this low uptake are unclear. This thesis explores the role of psychological, social and cultural factors in the low uptake of CRC screening in SE London.

Mixed methods were employed where a narrative synthesis examined the beliefs of various ethnic minority and socio-economic groups about the FOBT; a qualitative study explored the beliefs of 50 people of Black African, Black Caribbean and White British backgrounds from SE London; and a prospective questionnaire study (n=507) identified the demographic and psychological predictors of screening intentions and uptake. The narrative synthesis, interview topic guide and questionnaire were underpinned by Theoretical Domains Framework (TDF; Michie et al 2005).

Findings of the narrative synthesis indicated a dearth of research examining both ethnicity and SES factors together. The qualitative study highlighted many similarities in the views of participants from the three main ethnic groups after considering SES. The survey indicated intentions and participation in CRC screening were underpinned by psychological and demographic factors, where psychological factors mediated the impact of ethnic differences. Although SES was not related to screening intentions or uptake, more deprived groups were significantly less likely to make an informed choice about screening.

This thesis has bridged an important gap by examining the beliefs of Black African and Black Caribbean who have been previously neglected from research. Exploration of ethnicity and SES and the integrated use of a theoretical framework are distinct strengths of this thesis. These findings can help inform the design of interventions to influence screening uptake.

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This thesis is dedicated to my wonderful parents, Rampal & Manjula; all that I am or hope to be, I owe to them.

## **Abbreviations**

BCT – Behaviour change technique

CRC – Colorectal cancer

FOBT – Faecal occult blood test

HBM - Health Belief Model

IMD Index of Multiple Deprivation

SES – Socio-economic status

SD – Social Deprivation

SCT - Social Cognitive Theory

TDF - Theoretical Domains Framework

TPB – Theory of Planned Behaviour

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# **Chapter One**

## **Thesis Overview**

### **1.1 Chapter overview**

This chapter aims to provide an introduction to the thesis, an overview of the colorectal cancer screening programme in the UK, describe screening uptake patterns, the aims and objectives of the research and finally, present an outline of the included chapters.

### **1.2 Background**

Colorectal cancer (CRC), also known as bowel, colon or rectal cancer, is the fourth most common cancer in the UK and the third most common cancer in both men and women (Office for National Statistics 2012). With approximately 40,695 new cases and 13,000 deaths in 2010, CRC is a leading cause of cancer morbidity and mortality in the UK. (ONS, 2012a). Early detection is associated with improved survival prospects, involving less aggressive treatment regimens and fewer complications (Department of Health 2011). However, cancer survival rates in the UK are relatively poor compared to other European countries, with late presentation and diagnosis being cited as major contributory factors (Department of Health 2011). Recognition of these shortcomings prompted the initiation of disease specific national cancer screening programmes for breast and cervical cancer, and more recently for CRC. Early diagnosis of cancer is thus a key priority for the health service and has been integrated within governmental policy, titled: ‘Improving Outcomes: a strategy for cancer (Department of Health 2011).

The UK national screening programme for CRC was established in 2006 to enable the early detection of CRC in males and females aged between 60 and 69 years. From April 2010, the

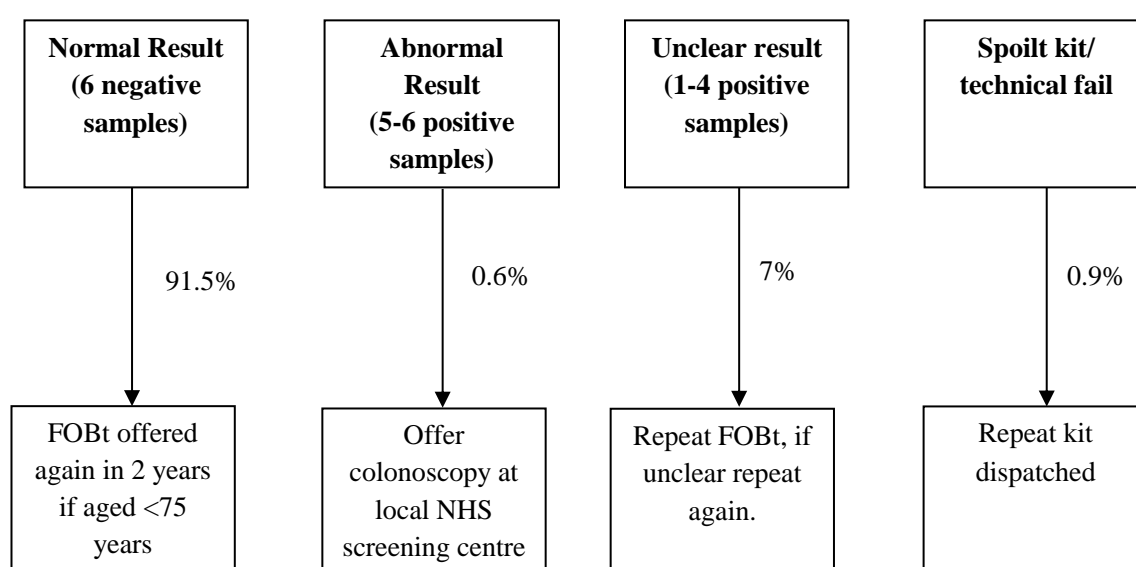
age range for CRC screening was extended to 75 years and this is gradually being implemented throughout England. Screening is offered biennially through the Faecal Occult Blood test (FOBt) to detect hidden traces of blood in the faeces, which can be a common occurrence in people with CRC and those with precancerous colonic polyps (Public Health England 2013). A Cochrane review of randomised control trials of the FOBt concluded there was sufficient evidence to suggest that screening can reduce mortality from CRC by 16% (Hewitson, Glasziou et al. 2008). CRC screening differs from the pre-existing breast and cervical cancer screening programmes in that it is the first UK mass screening programme to include both men and women and FOBt completion is undertaken by individuals themselves. The next section describes the screening process in detail.

### **1.3 The screening process**

People who are invited for CRC screening in England are identified through a web based database of all NHS patients registered with a GP (Halloran 2009). Beginning at the age of 60, identified individuals usually receive a postal invitation for screening around the time of their birthday, repeated every two years until they reach the upper age limit of 75 years. Accompanying the screening invitation letters is an information booklet about CRC and the screening process. Approximately two weeks after receiving the screening invitation letter, individuals receive a second letter containing the FOBt kit, cardboard spatulas, instructions for completion and a 'prepaid' envelope to return the completed FOBt kit. Individuals are asked to return their completed FOBt kits within 14 days of the first sample being collected. As screening is centrally organised, dispatch and return of FOBt kits is undertaken by one of the five national laboratories or screening 'hubs' that each cover a major regional area. The screening hub for London is based at St. Mark's Hospital (Northwick Park) in North West London.



Each FOBt kit contains a total of six windows where individuals are required to collect and apply a small faecal sample to two windows, on any three days within the 14 day deadline. Unlike other countries, there are no dietary restrictions for completing the FOBt as the kits employed in the English screening programme are not rehydrated because this may increase the rate of false positive results (Public Health England 2013). The possible outcomes following return of a completed FOBt kit are illustrated below in figure 1.1, where approximate proportions of the incidence of each outcome are also given.



**Figure 1.1:** The screening pathway for the CRC screening programme in England (Logan, Patnick et al. 2012).

As evident in figure 1.1, the majority of people who complete and return a FOBt receive a ‘normal’ result, with considerably smaller proportions receiving an ‘unclear’ or ‘abnormal’ result. People who do not return a completed FOBt kit within four weeks of initial dispatch receive a reminder letter alongside another FOBt kit. Screening invitees are given a total of 13 weeks to complete and return their FOBt after which their current screening episode is closed. For those who do not respond to the initial screening invitation or reminder letter, screening is offered again in two years, provided individuals are still within the age range.

Now that the screening process has been outlined, the next section will outline socio-demographic patterns in the uptake of CRC screening.

## **1.4 Uptake of Screening**

Analysis of the first 2.6 million screening invitations across England revealed that uptake of screening was 54%, which is consistent with uptake rates demonstrated in Australia and the Netherlands (von Wagner, Baio et al. 2011). Although the national uptake of screening appears promising, notable differences relating to ethnic and socio-economic variation have been found. Uptake of screening in areas of high ethnic diversity was found to be as low as 38% (von Wagner, Baio et al. 2011). With regards to area level socio-economic deprivation, uptake of screening in the least deprived areas was 61%, much higher than 35% uptake in the most deprived areas (von Wagner, Baio et al. 2011).

In South East London, where the empirical research in this thesis was undertaken, uptake of screening has been found to be particularly low. Uptake of screening in Lambeth was 38.5% and 38.4% in Southwark at the end of 2010 (South East London Bowel Cancer Screening Centre 2010). Furthermore, uptake of screening in Lambeth and Southwark was lower than uptake in other South East London boroughs including Bromley (53.98%), Bexley (50.50%), Lewisham (43.10%) and Greenwich (47.41%) (South East London Bowel Cancer Screening Centre 2010). In a more recent evaluation by the London screening hub, uptake had slightly increased in Lambeth and Southwark, 40% and 42% respectively, but remained lower than other neighbouring boroughs, in the first half of 2012 (Stewart 2012). These differences in uptake compel us to investigate the demographic characteristics of Lambeth and Southwark which may suggest the reasons why uptake of CRC screening is lower in these areas. The boroughs of Lambeth and Southwark are amongst the most deprived boroughs in London. Lambeth, being the second largest inner London borough, is ranked as the fifth most deprived and Southwark as the twelfth most deprived London borough (NHS Lambeth 2009,

NHS Southwark 2010). Moreover, Lambeth and Southwark are also highly ethnically diverse and according to the latest census results, approximately 26% of residents in each borough are from Black/African/Caribbean backgrounds (Office for National Statistics 2012b). This proportion of Black African/Caribbean individuals residing in Southwark and Lambeth is comparatively higher than other neighbouring boroughs including Bromley (6%), Tower Hamlets (7.3%) and Wandsworth (10.6%) and (Office for National Statistics 2012b).

Reasons for the lower uptake of screening in South East London are unclear but could pertain to high mobility of London residents, problems with undeliverable mail and potentially greater use of private healthcare in London (Logan, Patnick et al. 2012). On the other hand, low uptake may also represent informed choices not to participate for some people however for others, factors relating to ethnicity, deprivation, culture and psychological beliefs may hinder informed responses to screening invitations. In this thesis, psychological beliefs refer to individuals' thoughts or cognitions about a given behaviour within a social context, known as social cognitions. By nature, these social cognitions are factors that are potentially amenable to change. Thus, by identifying the factors that drive uptake (and non-uptake) of screening, strategies that target these underlying processes can be developed to enhance the informed uptake of CRC screening. The contribution of these factors to screening uptake is largely unknown and information on this topic is urgently required to optimise the impact and equity of the national screening programme. The London boroughs of Lambeth and Southwark have a higher than average proportion of residents from African and Caribbean groups, yet no research in the UK has investigated what members of these groups think about colorectal cancer screening via FOBt, or compared their views to those of White British people. The distinct contribution of this thesis is using a comprehensive theoretical framework to examine the psychosocial factors underpinning CRC participation decisions and identifying the possible determinants of low uptake within an ethnically and socio-economically diverse South East London population.

## **1.5 Key research questions**

1. What are the beliefs about CRC screening of the main ethnic groups of South East London – African, Caribbean and White British people, and are there any differences between groups after considering socio-economic factors?
2. Are low rates of screening uptake in South East London underpinned by ethnicity, socioeconomic factors or an informed choice not to participate?
3. Do psychological beliefs mediate the impact of demographic factors on screening uptake?

## **1.6 Overview of Chapters**

Chapter two provides the background to the thesis. The chapter begins with an overview of uptake of CRC screening in the UK and presents some evidence for ethnic and SES inequalities in health as well as screening uptake. It also critically appraises the various definitions and indicators of ethnicity and SES and outlines the definitions that are used in this thesis. The chapter concludes by presenting a number of possible mechanisms through which ethnicity and SES may influence the uptake of screening

As a foundation to understanding differential patterns of screening uptake, chapter three outlines the theoretical basis to the research to be presented in this thesis. The chapter is in three parts: the first discusses how screening is offered and considers the concept of informed choice. The second part of the chapter appraises several psychological theories from the social cognitive perspective. However, the social cognition approach is not without its limits and a discussion of potential methodological issues follows the overview of theories. The chapter ends with an outline of the selected theoretical approach with a rationale for its selection in this thesis.

To build on the concepts introduced in chapters two and three, a narrative synthesis seeking to systematically examine the patterning of psychological beliefs about CRC screening across different ethnic and socio-economic groups is presented in chapter four. This chapter has three elements: the first concerns studies that focused on SES, the second focuses on studies that examined ethnicity and the third section focuses on studies that examined psychological beliefs according to both ethnicity and SES. The findings illuminated some differences but many more similarities in the views of various ethnic and socio-economic groups. The review also discusses factors that may hinder informed responses to screening invitations.

Chapter five presents a qualitative interview study undertaken to explore the beliefs about CRC screening of the three main ethnic groups of South East London: White British, Black African and Black Caribbean people of varying SES.

The findings of the qualitative study in chapter five were used to develop the questionnaire employed in chapter six in order to quantitatively examine the predictors of screening intentions and uptake in a prospective questionnaire study. The influence of demographic factors and psychological constructs was assessed and examination of relationships was undertaken through mediation analysis. In addition, the extent to which uptake of screening was based on informed choice was also examined.

Chapter seven, the final chapter, presents a critical appraisal of the findings of the research undertaken in this thesis alongside a discussion of possible intervention strategies and implications for future research.

## **Chapter Two**

### **Conceptualising Ethnicity and SES**

#### **2.1 Chapter overview**

A wealth of research suggests that uptake of colorectal cancer (CRC) screening may differ by individuals' socio-demographic factors such as ethnicity and socio-economic position. This chapter begins with an overview of the social disparities that have been found to exist in the uptake of CRC screening by people with different ethnic and socio-economic backgrounds, drawing on national and international evidence. A further aim of this chapter is to discuss the conceptual issues regarding ethnicity and socio-economic status (SES), problems with the measurement of these categories and finally, set out the definitions that will be used in this thesis.

#### **2.2 Uptake of CRC screening in the UK**

Evaluation of the second round of the CRC screening programme pilots across England highlighted a modest uptake rate of 52.1% (Weller, Coleman et al. 2007), which was lower than the 58.5% uptake rate reported in the first round of screening (UK Colorectal Cancer Screening Pilot Group 2004). Uptake was significantly lower in people originating from the Indian subcontinent, people living in areas of high deprivation, older people, those invited for screening for the first time, and men (Weller et al., 2007). The original pilot assessing the feasibility of introducing screening, along with subsequent evaluations, took place across the West Midlands. Therefore, many South Asian invitees were included because this group constituted the largest ethnic minority population of the area. However, there is little information on the responses of Black African, Caribbean and Chinese groups in the UK to being invited for screening, as these groups were not focused upon in the original screening

pilots. This thesis will partly bridge this gap by examining the views of Black African and Black Caribbean people.

Research examining the relationship between ethnicity and uptake of CRC screening via the FOBt in the UK is limited. In contrast, much research attention has been directed to studying ethnic differences in the uptake of screening in the US, mainly regarding people of African American and Hispanic origin. However, the extent to which USA uptake patterns can be applied to the UK remains unclear given the different ethnic groups and also because CRC screening in the USA is not delivered as a routine national screening programme. Instead, screening is opportunistically offered when individuals present to physicians for routine health concerns. The definition of uptake thus varies across studies, making it difficult to compare the findings of US studies with UK based studies (Szczepura 2003). Nevertheless, an overwhelming number of studies in the US have consistently reported lower uptake of screening by ethnic minority groups such as, African American, Hispanic, Latino and Chinese American people (Ata, Elzey et al. 2006, Greiner, Born et al., 2005, Shokar, Carlson et al. 2008, Tseng, Holt et al. 2009, Walsh, Kaplan et al. 2004, Brenes and Paskett 2000).

Although the CRC screening programme has been relatively recently implemented in the UK, evidence from the well-established breast and cervical cancer screening programmes suggests there is some ethnic variation in the uptake of these programmes. The majority of research however, focuses on South Asian women, in whom uptake rates have found to be significantly lower than White British women, (Szczepura, Price et al. 2008, Price, Szczepura et al., 2010). In contrast, relatively high rates of cervical cancer screening uptake, equivalent to national averages, have been reported in African and Caribbean women (as cited by Szczepura, 2003a). However, given that breast and cervical screening programmes only apply to women, there is no evidence on African and Caribbean men's responses to cancer screening programmes, a gap that will be bridged by this thesis.

The lack of ethnic monitoring data collected at the primary care level means it is difficult to assess whether ethnic differences in the uptake of CRC screening really exist outside research settings (Robb, Power et al. 2008). The few UK based studies, such as by Robb et al., (2008), examining ethnic differences in CRC screening, have focused on participation in flexible sigmoidoscopy (FS) which involves participants from a larger trial designed to assess the efficacy of FS as a method of screening (Atkin, Edwards et al. 2010). Exploration of socio-economic factors in relation to CRC screening uptake has, however, received greater research attention. In the evaluation of the second round of the CRC screening pilot, there was a significant decline in uptake rates with increasing levels of socioeconomic deprivation (Weller et al., 2007). Furthermore, a study undertaken in Scotland by McCaffery, Wardle et al., (2002) found that those living in areas of high socioeconomic deprivation were less likely to return a questionnaire on their interest in CRC screening by sigmoidoscopy, were less likely to express an interest in undergoing screening and, of those who did, they were least likely to attend screening appointments. However, as noted by von Wagner, Good et al., (2009), there are key features of the UK CRC screening programme which should minimise social inequalities in screening uptake. There is no direct or indirect financial cost related to participating, individuals would not need to take time off work as the test is completed at home, is self-administered and returned in the “freepost” envelope which is provided with the test kit. Yet these factors did not prevent socioeconomic differences in screening uptake from occurring in both rounds of the FOBt screening pilots (von Wagner, Good et al. 2011).

The possible mechanisms through which ethnic and socio-economic differences may impact uptake of screening will be discussed later in this chapter. Prior to that, the next section will outline and critically appraise key conceptual issues regarding the measurement of ethnicity and socio-economic status.



## 2.3 Ethnicity

The 1990s saw a shift in British health policy towards tailoring services to meet the needs of local communities in order to overcome the health disadvantage experienced by people of different backgrounds (Gerrish 2000). To facilitate understanding experiences of health, illness and engagement in health behaviours such as screening, researchers have often explored the impact of social, cultural and economic factors that vary between different groups. The concepts of 'race', 'culture' and 'ethnicity' are used to divide populations and, as such, feature frequently in explanations of different health and behaviour patterns.

Definitions of what constitutes 'ethnicity' or 'race' have evolved over time and have been found to vary between countries (Bartley 2004). The term 'race' refers to groups of people who are thought to differ from each other according to biological characteristics such as skin colour, hair type and shape of specific features such as eyes and nose (Bhopal 2007). As noted by Bhopal, (2007), historically the classification of race based on biological characteristics had profound negative social and political repercussions: for instance classifying particular races as "criminal" or "imbecile", and more extremely, the holocaust. The use of the term 'race' is thus regarded as a socially and politically constructed concept that has been used to justify the inferior treatment and greater exploitation of certain groups in a given society (Bartley 2004). Whilst 'race' has largely diminished from use in the UK, it still features as a prominent aspect of American conceptualisations (Bhopal 2007).

In contrast to "race," "ethnicity" refers to cultural differences in populations on the basis of geographical origin, language and/or religion (Bartley 2004). Recent conceptualisations encompass ethnicity as an indicator of the process by which people create and maintain a sense of group identity and solidarity to distinguish themselves from others (Cornell and Hartmann 1998).

Bulmer (1996, p.35) conceptualised an ethnic group as:

*“a collectivity within a larger population having real or putative common ancestry, memories of a shared past, and a cultural focus upon one or more symbolic elements which define the group’s identity, such as kinship, religion, language, shared territory, nationality or physical appearance. Members of an ethnic group are conscious of belonging to an ethnic group.”*

Ethnicity can also be viewed as an external category that people, or groups, oppose on one another. However, one may not necessarily agree or identify with the category they have been assigned. Furthermore, using such a categorical classification of ‘ethnicity’ may create an imbalance in power between particular groups and lead to the existence of an ‘us’ and ‘them’ mentality (Hogg 2006; social identity theory). Therefore, a more useful definition of ‘ethnicity’ may be to view it as an extension of identity, a positive process of group formation and cohesion (Mason 1991).

From the discussion so far, it is clear that ‘ethnicity’ is a multi-faceted concept, based on elements of physical appearance, ancestry, cultural aspects, identity and religion. Given the many different components of ‘ethnicity’, it is important to use clear definitions of groups included in research studies as imprecise use of the term ‘ethnicity’ may lead to a loss in its analytical value (Ahmad and Bradby 2007). The next section will examine ethnic inequalities in health to further analyse the concept of ‘ethnicity’.

## **2.4 Ethnic inequalities in health**

Although the term ‘ethnic group’ technically refers to all groups, majority or minority, it is often used to refer to groups who are the numerical minority (Bartley 2004). Therefore, identifying and describing differences between ethnic groups implicitly infers the inferiority

and superiority of different groups, and as such, a difference in power (Bartley 2004, Gerrish 2000). According to Bartley (2004), applying ‘ethnicity’ to understand ‘ethnic differences in health’ can be problematic as it implies that the health problems of particular (ethnic minority) groups are due to their ‘culture’ or ‘ethnic’ background. Moreover, attributing health differences to culture can be equated to attributing differences to biology, as in the concept of ‘race’ outlined above. ‘Blaming’ ethnic minority groups for the increased prevalence of a particular illness implies that they should adopt the cultural practices of the ‘majority’ group in order to overcome disparities in health (Bartley 2004). Furthermore, this perspective fails to examine the reasons *why* different ethnic groups have different experiences of health and illness. Nazroo (1998) has argued that inequalities in health between members of different ethnic groups occur within a wider framework of socio-economic inequalities. Thus, it is better to understand ethnic differences in health by examining where members of different ethnic groups are situated within social structures, rather than by examining the cultural or biological differences between the groups (Bartley 2004). In a later section, inequalities existing between members of single ethnic groups will be discussed alongside an examination of the role of SES factors such as education, income, social class and income.

## **2.5 Measurement of ethnicity in the UK**

Although recording of ethnicity is not yet routine practice in primary care, a shift is occurring and as a result, greater ethnic monitoring is beginning to take place within the NHS. A key measure of ethnicity in the UK is via the national census that occurs once every ten years. Table 2.1 (on page 27) outlines the ethnicity categories that were used in the recent 2011 census. The number of categories and sub-categories featured in the ethnicity question of the UK census reflects the complexity of the concept. Furthermore, the juxtaposition of ‘colour’ (e.g. White, Black) with nationality/geography (e.g. British, Caribbean) as well as combinations of categories such as, Mixed White and Black

Caribbean, signifies a further problem with the measurement of ethnicity (Bhopal 2007). It can be argued these categories may not be completely compatible with people's conceptualisations of their own identity and thus may not capture all ethnic groups accurately. Moreover, as noted by Bhopal (2007), in a seminal textbook, census questions do not fully encapsulate 'ethnicity' as information relating to language and religion is not collected that may be more relevant for particular groups such as those originating from South Asia. However, health researchers often use the categories set out in the census to measure ethnicity. Given that the ethnicity questions in the census were developed on the basis of a pragmatic and political system to examine population characteristics, the appropriateness of using these categories for research examining social or cultural differences in health, or health service utilisation, is questionable (Gerrish 2000). Nevertheless, as argued by Aspinall, (2001), 'ethnicity' as a term encapsulating broad historical processes of colonialism, migration and discrimination that are reflected in the census categories, may be useful for studying inequalities in access of health and social care services. Whilst multidimensional information regarding ethnicity such as country of birth, years in country residence and religion, are likely to be useful, it may not always be practical to collect such detailed data, for instance when there are time constraints for responders (Aspinall 2001).

As noted earlier, the vocabulary used to describe "ethnic minority" populations varies and changes over time and place and, according to social and political contexts. For instance, terms such as 'black and minority ethnic (BME)', 'ethnic minority' and 'ethnic groups' are often used interchangeably in research and practice (Bhopal 2007). Moreover, the organisation in the UK that is responsible for campaigning for ethnic equality is the 'Commission for Racial Equality' and the primary laws are the 'Race Relations Acts' (Bhopal 2007). The dynamic and changing facets of 'ethnicity' coupled with the lack of clarity in definition certainly raises the question whether conceptualising 'ethnicity' as a fixed category, assigned to individuals, can be objectively measured. Several researchers

have argued for the measurement of ethnicity information to be focused and specific to the research in question (Aspinall 2001, Bradby 2003, McKenzie and Crowcroft 1996).

**Table 2.1:** *Ethnicity categories as featured in the 2011 UK census*

<b>Ethnic group</b>	
White	English/ Scottish/ North Irish/ British
	Gypsy or Irish Traveler
	Any other white background
Mixed/multiple ethnic groups	White and Black Caribbean
	White and Black African
	White and Asian
	Any other Mixed/multiple ethnic group
Asian/Asian British	Indian
	Pakistani
	Bangladeshi
	Chinese
	Any other Asian background
Black/ African/ Caribbean/ Black British	African
	Caribbean
	Any other Black/ African/ Caribbean background
Other ethnic group	Arab
	Any other ethnic background

## 2.6 Definition of ethnicity employed in this thesis

Despite the different definitions of ethnicity discussed so far in this chapter, there is no consensus on the appropriate terms that should be used in the scientific study of ethnicity and health (Bhopal 2007). This thesis will follow a pragmatic yet flexible approach in the conceptualisation and measurement of ethnicity. The definition of ‘ethnicity’ will refer to the “group a person belongs to as a result of a mix of cultural factors including language, diet, religion and ancestry” (Bhopal 2007; p.33). The term ‘ethnic minority’ will be used to refer to minority populations of non-European origin that are characterised by their non-White

origin (Bhopal 2007). Similarly, 'White British' will be employed to describe people with European ancestral origin who reside in the UK. Moreover, 'South Asian' will refer to populations originating from the Indian subcontinent including India, Pakistan, Bangladesh and Sri Lanka. 'Black African' will be used to describe people from Africa, and the term 'Black Caribbean' will refer to those who originate from the West Indies, or self-identify themselves as such.

Acknowledging the complexities surrounding the measurement of ethnicity, participants in the empirical studies in this thesis (chapters five and six), will be allowed to self-report their ethnicity in their own terms, in an attempt to overcome some of the conceptual and practical challenges outlined earlier in this chapter. For instance, using pre-defined ethnicity categories may not accurately reflect how individuals perceive their own ethnic identity. Furthermore, given the increasingly multi-cultural population of South East London, use of pre-defined ethnicity categories may lead to the omission of some groups who do not perceive themselves as belonging to the specified groups. The self-defined ethnic group labels will then be linked to the census categories as recommended by Aspinall (2001). When describing ethnic groups in research studies, this will be based on the terminology used by original authors. Table 2.2 overleaf, displays the commonly studied ethnic groups in American studies (adapted from Bhopal 2007). The terminology outlined in table 2.2 will be used in addition to the terms in table 2.1 to develop search terms for the systematic research review in chapter four (see appendix 4.1 for the search terms).

**Table 2.2:** Terminology used to describe ethnic groups in the US

<b>Ethnic group</b>	<b>Definition</b>
African American	This is a specific term that signifies people of African ancestry and their country of migration (America). However, it is often used to describe Caribbean/ West Indian participants along with the term ‘Afro-Caribbean’, thus neglecting the heterogeneity that exists between the groups
Asian	Whilst the term in the UK is used to refer to people originating from the Indian subcontinent, in the USA it is commonly used to refer to people originating from the Far East including China, Japan, Korea and Philippines
Black	This term relates quite closely to the concept of ‘race’ and refers to people whose origins lie in sub-Saharan Africa. In some instances, ‘Black’ is used to represent all non-White minority populations
Caucasian	Also relates to ‘race’ and is another synonym for ‘White’. The term has largely been abandoned due to the heterogeneity and lack of geographical relevance today.
Hispanic	This term is widely used and often interchangeably with ‘Latino’, referring to people originating from Spain as well as people of Latin American origin with Spanish or Portuguese ancestry
Native	This term relates to migration status and birthplace. It is often used interchangeably with ‘Indigenous’ and refers to minority groups that originally populated an area e.g. Native Americans, and also differentiates majority group participants from recent migrants e.g. native French.

## 2.7 Socio-economic status/situation

There is a social gradient in health where people with a lower socio-economic position in society have greater illness, disability, distress, as well as a lower life expectancy than those

who have a higher socio-economic position (Marmot, Allen et al. 2010). Furthermore, there is also some evidence of reverse causality where poor health can contribute to socio-economic hardship by increasing the risk of unemployment, low income and dependence on welfare benefits. Throughout the literature, terms such as “social class”, “socio-economic status” and “social status” are used inter-changeably to distinguish those at the top and at the bottom of a particular society’s social structure (Bartley 2004). The number of terms available indicates the complexities of defining, measuring and interpreting “socio-economic” factors, many of which will be unravelled as this section progresses. The next section will briefly examine inequalities in health according to SES.

## **2.8 SES inequalities in health**

Theories that outline the relationship between SES and health focus on three main mechanisms. The first mechanism is a materialist one where those with higher incomes are able to purchase more nutritious foods, have better housing, live in safer environments and have better access to healthcare (Grundy and Holt 2001). The second mechanism is concerned with behavioural or lifestyle factors, such as smoking, diet, alcohol consumption and the appropriate use of health care that may vary according to cognitive ability and ease of information access (Grundy and Holt 2001). The third mechanism focuses on psychosocial factors including empowerment, relative social status, social integration, exposure to life stressors and low autonomy in areas such as work (Grundy and Holt 2001). It is likely that the mechanisms through which one’s socio-economic position affects health are similar to the mechanisms that influence uptake of health behaviours such as screening. These mechanisms will be discussed in more detail later in this chapter.

## **2.9 Measurement of SES**

As with ‘ethnicity’, the measurement of ‘socio-economic’ factors has evolved considerably



over time. Physical strength, intelligence and parentage were used as indicators on which social stratification took place in the 19<sup>th</sup> century. However, more recent conceptualisations include indicators of area deprivation, wealth, income, education and occupational status (Bartley 2004). Such conceptualisations of SES evoke a sense of inequality in resources and prestige. In relation to resources, terms such as “poverty” and “deprivation” are used to describe those who lack material possessions, wealth and income. Prestige related measures, on the other hand, refer to individuals’ status in a social hierarchy, depending on occupational status, income and educational attainment (Bartley 2004). Measures such as resources and prestige tend to tap just one dimension of SES, typically income or wealth. Given their relative simplicity, SES measures appear to be critical to address questions of whether socioeconomic inequality causes health outcomes (Nazroo 1998). However, the validity of the measures of social position is based on their underlying conception of SES, which is clearly multi-factorial. Furthermore, the relationship between any particular measure of SES and health is likely to vary across different social and ethnic groups as well as age and gender (Nazroo 1998).

SES is a multi-faceted concept that incorporates a combination of socio-demographic factors (area of residence), social and economic status (educational attainment, car ownership, employment, income, occupational social class, housing tenure status) and social environment (housing conditions, social capital and social support). These factors are deemed as being clustered but are individual indicators of SES and, as such, will be reviewed in the following section, supported with information from the seminal Public Health Observatory Handbook of Health Inequalities Measurement (Carr-Hill, Chalmers-Dixon et al. 2005)

## **2.9.1 Socio-demographic factors**

### **Area of residence**

People can be distinguished according to their place and/or neighbourhood of residence, with areas with different postcodes allocated different social and financial values in the UK by organisations such as local authorities and the Office of National Statistics (ONS) (Carr-Hill, Chalmers-Dixon et al. 2005). Clustering of groups in order to save on housing costs or to be in close proximity to local industry and jobs has meant that traditionally, the rich have lived with the rich and the poor have lived with the poor. Car and home insurance brokers have also long used this neighbourhood level information to calculate risk of crime and damage. In relation to health, a number of associations have been reported with place of residence. For instance, there is a well documented divide in health between people living in the north and south of England, with morbidity and mortality both being higher in the north (Carr-Hill, Chalmers-Dixon et al. 2005). Moreover, those living in inner city areas, which are associated with lower quality housing, over-crowding and high ethnic variation, have been found to have significantly poorer health compared to those living in suburban areas (Carr-Hill, Chalmers-Dixon et al. 2005). However, the mechanisms through which area of residence impacts health are not clear and are particularly difficult to establish given the refinement of area boundaries over time. Furthermore, the setting and adjustment of these area boundaries is governed by local council and electoral wards and thus may not be compatible with the boundaries perceived by communities themselves (Carr-Hill, Chalmers-Dixon et al. 2005). Perceived area boundaries may fall outside or be a minute fraction of the boundaries set by the authorities, and as such, may not accurately reflect neighbourhood deprivation levels, quality of housing and provision and access of local services experienced by individuals compared to the rest of the constituency. A further problem with classifying individuals by area measures is the assumption that alike people live near alike people, thus disregarding any variation in individuals' or family's characteristics such as level of education or occupational status (Braveman, Cubbin et al. 2005).

## **2.9.2 Social and economic indicators**

### **Educational attainment**

Educational attainment is viewed as an indicator of social position where higher attainment reflects an advantage in social position. A number of advantages are noted of using level of education as an indicator of SES. Firstly, it is a relatively constant measure as there is usually little change in people's educational attainment after the age of 25, unless higher degrees are pursued (Carr-Hill, Chalmers-Dixon et al. 2005). Secondly, as level of education is rarely influenced by illness for adults, unlike income and occupation, the relationship between health and education can be independently examined. Another reason is that people's educational attainment is relatively easy to measure and information is more comparable, internationally and over time, than information regarding occupational class (Carr-Hill, Chalmers-Dixon et al. 2005).

The requirement of a compulsory level of education in the UK has meant that meaningful differences in health and illness have not been identified due to lack of variability in education (Carr-Hill, Chalmers-Dixon et al. 2005). The education system in the UK is divided into three parts: the first being primary school for ages 4/5 -11 years, followed by secondary education from 11-16 years and, recently the extension to tertiary education which has increased the compulsory education leaving age to 18 years (Education and Skills Act 2008, with effect from 2013). However, the compulsory leaving age has changed over time, from being 10 years in the 1880, 13 years in 1899, 14 years in 1918 and up to 15 years in 1947 (Carr-Hill, Chalmers-Dixon et al. 2005). Since 1972, the compulsory school leaving age has been 16 years until the recently planned extension

There are two main measures of education that are used in research: years of education completed and level of attainment. Years completed, as described above, reflects the age people leave education, whereas attainment reflects the qualifications gained e.g. Advanced

level examinations or undergraduate degree. A potential problem of using years of education completed is that attendance alone does not necessarily indicate what learning took place (Braveman, Cubbin et al. 2005). Furthermore, although there is little variability in educational years completed, gradual changes to the compulsory age as well as evolution of the education system and greater gender equality over time make it difficult to compare cohorts of older age to those who are comparatively younger (Carr-Hill, Chalmers-Dixon et al. 2005). In addition, whilst the number of people gaining higher educational qualifications has increased, there are still many highly educated people earning low incomes e.g. new graduates. Thus, level of education may not be enough on its own to indicate SES and should be considered in relation to other social, economic and demographic factors.

## **Income**

Perhaps the most commonly used measure of SES is a person's earned income. Often annualised, income refers to the availability of material resources as well as level of prestige (Marmot and Wilkinson 2009). Income is strongly associated with employment and occupational class, where a higher income generally indicates better employment and higher occupational class (Grundy and Holt 2001). For some people, income can be a sensitive topic to broach, reflected by the generally low response rates to income surveys (Grundy and Holt 2001).

Measures of income often refer to income gained from paid employment and as such, income can be a problematic indicator of SES for retired individuals and many of those who fall within the range of CRC screening (Grundy and Holt 2001). Moreover, older people may have multiple income sources such as a pension, or on some occasions, have money paid on their behalf e.g. housing benefit paid directly to landlords. Consideration of these additional sources of income has been found to reduce the differential in gross household income (income before tax is applied) between low and high SES groups (Marmot, Allen et al. 2010). It is evident that in order to collect all the possible sources of income a person has,

a large number of questions will be required which may further aggravate the already low response rate to income questions (Marmot, Allen et al. 2010). For people receiving welfare benefits due to ill health or disability, it is further difficult to examine any causal relationship between income and health as the two are highly correlated. Therefore, it may be more appropriate to consider older people's assets such as savings and ownership of homes and vehicles as these reflect 'economic reserves' that individuals are likely to draw on in later life (Berkman and Macintyre 1997).

As highlighted by Marmot, Allen et al., (2010), it is not always the case that those earning the lowest incomes find it the most difficult to make ends meet. One issue is considering the relationship of income to the number of dependants or people in the household. Consider the example of two colleagues who earn the same salary; one of them is a single parent of two children and also has to look after an elderly parent whilst the other is still single and lives alone. Thus, the two people are not directly comparable on income alone due to differences in their wider social situation (Marmot, Allen et al., 2010). Furthermore, living standards have been found to fall when income first begins to rise, possibly due to the loss of welfare benefits (Marmot, Allen et al., 2010). This initial drop in living standards against increased income results in a U-shaped relationship between income and measures of living standards, known as the 'cliff edge' (Marmot, Allen et al., 2010).

A related aspect to income is wealth, that is, the material and/or economic resources that are available to individuals and their families (Braveman, Cubbin et al. 2005). The composition and distribution of wealth in the UK has evolved over the last 20 years due to increased home ownership, new working patterns, growth in personal investment and the accumulation of wealth over the life course (Marmot, Allen et al., 2010). Therefore, to fully understand people's economic position, measures beyond income alone will be required.

## **Employment status**

As well as being an indicator of income, employment status is also a commonly used indicator of social position where unemployment is associated with social disadvantage. Employment, as defined by The International Labour Organisation (ILO) in 1982 (Husmanns 2007) includes all people within the ‘economically active population’ who for a specified time frame are engaged in a: ‘paid employment’, b: are self-employed or c: are part of an enterprise but not at work. The ILO outlined a similar definition for unemployment, as affecting those who are available for work but without work or, who are actively seeking work. According to these definitions, employment and unemployment are thus mutually exclusive such that individuals who are seeking employment but engage in casual work in the meantime, of any type, are still classified as employed (Carr-Hill, Chalmers-Dixon et al. 2005). There is also a distinction between people seeking work who could be ‘gainfully employed’ and people who are not seeking paid work, such as carers of ill family members (Carr-Hill, Chalmers-Dixon et al. 2005).

From the discussion above, it is apparent that ‘employment’ reflects a complex and broad concept, encompassing an array of working circumstances. In contrast, the relatively simple concept of ‘under-employment’ includes people who are classified as ‘employed’ but still may be looking for further employment. This may be for various reasons but essentially implies that individuals’ employment is inadequate and incompatible with their occupational training and work experience (Carr-Hill, Chalmers-Dixon et al. 2005). ‘Under-employment’ is also characterised by low income, under-utilisation of skills and low productivity (Carr-Hill, Chalmers-Dixon et al. 2005). Moreover, there are three criteria for classifying people who are ‘under-employed’, including working reduced hours, working on an involuntary basis and seeking or being available for additional work during the same period (Carr-Hill, Chalmers-Dixon et al. 2005).

Given the broad measures of ‘employment’, rates of employment have been found to vary according to type of employment measure used in the US (Carr-Hill, Chalmers-Dixon et al. 2005). One way of enhancing the robustness of employment status as an indication of SES is to consider it alongside occupational information, discussed next.

### **Occupational social class**

The classification of social class based on occupation, and therefore, partly on wealth, first occurred in the census of 1911. The original rationale for collecting occupational class information was to facilitate the analysis of fertility and infant mortality (Carr-Hill, Chalmers-Dixon et al. 2005). Although the classification of occupational social class has changed over time, it is still used today to compare death rates, also known as, ‘standardised mortality ratios’, between different social classes (Carr-Hill, Chalmers-Dixon et al. 2005). However, it is not clear to what extent the extensively modified occupational social class classification reflects changes in occupational class structure since 1911. Thus, it is questionable whether differences in occupational social class indicate real differences in individuals’ lives and relative prosperity

The most current classification of occupational social class in use is the National Statistics Socio-Economic Classification (NS-SEC), formulated for the 2001 census. The NS-SEC defines occupation as a structural position that is considered to shape the life chances of individuals and their families. These life chances depend on the occupational division of labour and the material and symbolic advantages derived from it (Office for National Statistics (ONS, 2000). As such, inequalities in morbidity and mortality according to occupational social class thus represent differences between social class positions (Carr-Hill, Chalmers-Dixon et al. 2005). The NS-SEC is comprised of eight divisions that sub-divide into seventeen different operational categories. An abridged five category version of the NS-SEC also exists that includes: 1) managerial, administrative and professional

occupations, 2) intermediate occupations, 3) small employers and technical occupations, 4) lower supervisory and technical occupations and 5) semi-routine and routine occupations (ONS, 2010). Table 2.3 below, outlines the full NS-SEC alongside all sub-categories.

**Table 2.3: NS-SEC analytic classes, operational categories and sub-categories (ONS, 2010)**

<b>Analytic Classes</b>	<b>Operational categories and sub-categories classes</b>	
1.1	L1	<b>Employers in large establishments</b>
	L2	Higher managerial and administrative occupations
1.2	L3	Higher professional occupations
		L3.1 'Traditional' employees
		L3.2 'New' employees
		L3.3 'Traditional' self-employed
		L3.4 'New' self-employed
2	L4	<b>Lower professional and higher technical occupations</b>
		L4.1 'Traditional' employees
		L4.2 'New' employees
		L4.3 'Traditional' self-employed
		L4.4 'New' self-employed
	L5	Lower managerial and administrative occupations
	L6	Higher supervisory occupations
3	L7	<b>Intermediate occupations</b>
		L7.1 Intermediate clerical and administrative occupations
		L7.2 Intermediate sales and service occupations
		L7.3 Intermediate technical and auxiliary occupations
		L7.4 Intermediate engineering occupations
4	L8	<b>Employers in small organisations</b>
		L8.1 Employers in small establishments in industry, commerce, services etc.
		L8.2 Employers in small establishments in agriculture
	L9	Own account workers
		L9.1 Own account workers (non-professional)
		L9.2 Own account workers (agriculture)
5	L10	<b>Lower supervisory occupations</b>
	L11	Lower technical occupations
		L11.1 Lower technical craft occupations
		L11.2 Lower technical process operative occupations
6	L12	<b>Semi-routine occupations</b>
		L12.1 Semi-routine sales occupations
		L12.2 Semi-routine service occupations
		L12.3 Semi-routine technical occupations
		L12.4 Semi-routine operative occupations



		L12.5 Semi-routine agricultural occupations
		L12.6 Semi-routine clerical occupations
		L12.7 Semi routine childcare occupations
7	L13	<b>Routine occupations</b>
		L13.1 Routine sales and service occupations
		L13.2 Routine production occupations
		L13.3 Routine technical occupations
		L13.4 Routine operative occupations
		L13.5 Routine agricultural occupations
8	L14	<b>Never worked and long-term unemployed</b>
		L14.1 Never worked
		L14.2 Long-term unemployed
*	L15	Full-time students
*	L16	Occupations not stated or inadequately described
*	L17	Not classifiable for other reasons

One advantage of the NS-SEC version outlined above is the inclusion of as many people as possible who are not in paid employment, such as full-time students or those who have never worked (Carr-Hill, Chalmers-Dixon et al. 2005). For people who are retired or no longer in paid employment, the NS-SEC allows classification with reference to individuals' previous primary occupation, although this may not be an accurate reflection of one's present SES. Furthermore, meaningful distinctions that were lacking in the terms 'manual', 'non-manual' and 'skill' that were once used in occupational classifications are no longer an issue in the detailed and clear conceptual framework of NS-SEC (Carr-Hill, Chalmers-Dixon et al. 2005). The NS-SEC distinguishes different levels of 'employment relations' between those who are employers and "buy" the labour of others, those who are self-employed and neither buy or sell their labour to others, and employees who sell their labour to employers. In general, NS-SEC categories are assigned to households rather than individuals per se, where the emphasis is on shared resources and conditions of family members (Carr-Hill, Chalmers-Dixon et al. 2005). To this end, one family member, usually the person responsible for the accommodation or the person with the highest income, is selected as the household reference person (HRP) to represent the position of the whole household.

Bhopal (2007) argued that occupation may not be a reliable measure of SES in the period following migration as many well-educated members of immigrant groups may have needed to take lower paid jobs when they initially arrived in the country in order to establish themselves. Furthermore, Bhopal (2007) noted that many immigrants who were in the managerial classes ran small businesses which often struggled financially, resulting in low income as well as working long and hard hours. Thus, the relationship between education, occupational social class, income and health may appear to be distorted due to migration and this should be considered when measuring the SES of immigrant populations.

## **Social Capital**

Originally a concept with roots in sociology, social capital refers to features of social organisation that provide resources to people through membership of social networks or communities in order to facilitate individual and collective action (Carr-Hill, Chalmers-Dixon et al. 2005). The assumption is that being a member of a social network increases one's opportunities for informal social control as well as increased access to information (Carr-Hill, Chalmers-Dixon et al. 2005). The extent to which individuals are embedded within their family relationships, communities and social networks, and have a sense of belonging, essentially underpin the concept of social capital (Morrow 1999). According to Putnam (1993), social capital can be measured by indicators such as the level of membership in any type of voluntary organisation, the extent of mutual trust between citizens and perceived reciprocity with regards to aid. According to these definitions, social capital can thus be considered as an indicator of social relations that combines both individual and area level aspects of SES.

There are three main forms of social capital: bonding social capital, bridging social capital and linking social capital. Bonding social capital reflects the extent to which a single, shared identity is prevalent in a given group, and tends to reinforce the confidence and homogeneity

of the group (Feinstein, Sabates et al. 2006). Bridging social capital, on the other hand, refers to social networks that go beyond homogenous entities and involves horizontally cross-cutting networks of different ethnic, cultural and socio-demographic groups (Feinstein, Sabates et al., 2006). The final form of social capital, linking social capital focuses on the connections people have with institutions of power and authority (Feinstein, Sabates et al., 2006). In contrast to bridging social capital, linking social capital is theorised in terms of vertical social networks within a social hierarchy as opposed to horizontal networks.

Closer examination of the social patterning of the different types of social capital indicates that those of lower SES tend to have higher levels of bonding social capital which acts as a protective factor (Feinstein, Sabates et al., 2006). However, people of low SES have also been found to have lower levels of bridging and linking social capital which limits their access to resources that are not locally available (Feinstein, Sabates et al., 2006). The opposite trend has been reported for people of higher SES, where levels of bridging and linking social capital are higher, allowing individuals to access a wide range of beneficial services (Feinstein, Sabates et al., 2006). In relation to health, studies in the UK have found that women who reported higher levels of bonding social capital and enjoyed living in their neighbourhoods, reported high reciprocity and high levels of community involvement and had better self-rated health, although no similar patterns were found for men (as cited by Carr-Hill, Chalmers-Dixon et al. 2005). In stark contrast, studies in Glasgow and Luton found that individual measures of social capital including perceived neighbourhood cohesion and the perception of a local identity were not related to self-rated health although no gender information was available (Carr-Hill, Chalmers-Dixon et al. 2005).

Whilst area of residence, educational attainment, income, employment status, occupational social class and social capital are indicators of SES, they are neither interchangeable nor sufficient to use alone. In the words of Braveman (2005), “one size does not fit all” when measuring SES in health research. Recognising that SES is a multi-faceted concept,

researchers are moving towards measures that include multiple indicators of SES, such as the index of multiple deprivation developed by the government, discussed next.

### **Index of multiple deprivation (IMD)**

The IMD measures relative levels of deprivation in small areas of England known as Lower Layer Super Output Areas (LSOA). The average number of households in England and Wales at the end of March 2011 was 672 (ONS, 2012b). Each LSOA has been appraised against 38 separate indicators across seven domains including income deprivation, employment deprivation, health deprivation and disability, education, skills and training deprivation, barriers to housing and services, living environment deprivation and crime (McLennan, Barnes et al. 2011). As well as providing a deprivation index for each domain, the domains are also weighted to derive a total 'IMD score' which indicates the extent of deprivation in any given area. IMD scores can also be used to rank every LSOA in England according to their relative level of deprivation. Furthermore, the IMD is a continuous measure and as such, there is no definitive cut-off point that below which some areas would be deemed as deprived and above which they are not (McLennan, Barnes et al. 2011). Rather than a single cut-off score of deprivation, researchers tend to use a cut-off value beyond which areas are deemed to be the *most* deprived, such as the most deprived 20% (most deprived quintile) of LSOAs in England (McLennan, Barnes et al. 2011).

The IMD is unique in including both a measure of deprivation as well as being a direct measure of poverty through data regarding the lifestyles and socio-economic circumstances of the people living in a given area (Department for Communities and Local Government 2011). However, there are limitations associated with the reliance on this measure of SES alone. Firstly, IMD scores cannot be compared over time because each area's score is influenced by the scores of every other area making it impossible to determine whether any change in IMD score reflects a change in deprivation or due to changes in the scores of other

areas (Department for Communities and Local Government 2011). Second, the IMD is not a measure of affluence thus an area that is ranked as least deprived is not necessarily the most affluent area (Department for Communities and Local Government 2011). Moreover, as IMD is a relative measure of deprivation in an area, there will be people who are deprived and not deprived within every area who cannot be distinguished by their IMD score. This gives rise to the problem of ‘ecological fallacy’ where conclusions about relationships at one level of analysis (such as areas) are extrapolated to another level (to individuals), leading to distorted and inaccurate results (MacRae 1994).

## **2.10 Definition of SES used in this thesis**

Multiple measures are used in this thesis to capture the different facets of SES. The research took place in two preselected London boroughs, Lambeth and Southwark that are known to be socially deprived. Moreover, postcodes were collected in order to derive IMD scores for individual neighbourhoods for the questionnaire survey only (chapter six). In addition, characteristics of individuals including their material and social resources were used as indicators of SES. These resources include educational qualifications, car ownership and home ownership. An individual level index of SES was thus created by combining responses to questions regarding educational qualifications, car ownership and housing tenure to create three categories of social deprivation, as used in previous studies (Crockett, Wilkinson et al. 2008, Wardle, Taylor et al. 1999, Wardle, McCaffery et al. 2004). People who both owned their homes and had educational qualifications were considered to have the lowest social deprivation (scored as 0). Those who either owned their homes or had educational qualifications were considered to have intermediate levels of deprivation (scored as 1) and neither owned their homes nor had educational qualifications were considered to have the highest social deprivation (scored as 2). Occupational status was also measured however social class according to the NS-SEC criteria was not considered in this thesis due to the majority of the sample being of, or close to, retirement age.

Now that the main of definitions of ethnicity and SES have been outlined, the final section of this chapter will examine how ethnic and SES differences are associated with the disparities in the uptake of CRC screening.

## **2.11 Ethnicity SES and CRC screening**

There is a common assumption that socio-demographic differences are likely to be the reason for health inequalities and differences in the uptake of health behaviours such as cancer screening. Although differences in health have been found to vary according to ethnicity, the findings should be treated with caution. As noted by Karlsen and Nazroo (2000), a major drawback is the use of one-dimensional definition of ethnicity that fails to consider the range of meanings underlying the concept such as the importance of ethnic identities. With regards to SES, Karlsen and Nazroo (2002) argued that many studies do not consider the role of socio-economic position when examining the relationship between ethnicity and health. This results in a skewed view that attributes differences to ethnicity when they may in fact reflect SES disparities among members of different ethnic groups. The use of more sensitive measures has shown that differences in socio-economic position contribute significantly to the apparent relationship between ethnicity and health (Karlsen and Nazroo 2002).

In some cases, there may be differences in health across ethnic groups that are due to additional factors beyond SES. For instance, deprivation endured by people from ethnic minority groups is likely to involve more than material disadvantage. Findings from Karlsen and Nazroo's (2002) study suggested that ethnic differences in health were mediated by perceptions of racial harassment and discrimination, such that those who perceived higher levels of racism and discrimination reported the poorest health.

In relation to CRC screening, as mentioned at the beginning of this chapter, a plethora of

studies have consistently found that uptake of CRC screening is much lower in some ethnic minority groups and those of low SES. Whilst studies rarely consider both ethnicity and SES factors together, of the ones that do, some important indications are evident. For instance, Christie, Nassisi et al.,(2006) found that uptake of screening was higher in Hispanic participants who were interviewed in Spanish than White American participants who spoke English. Closer examination of the data revealed that Spanish speaking Hispanic participants had higher educational attainment compared to White American participants. In another study, Green and Kelly (2004) were surprised to find high uptake of screening in their sample of African American participants who were predominantly low income. However, these participants resided in housing that was in close proximity to several healthcare centres which may have made it easier for them to access screening. This suggests that more attention should be paid to the environment in which people live. Bartley (2004) argued that areas in the UK with high concentrations of certain ethnic groups also experience lower levels of services and worse environment conditions, which exacerbate the disadvantage experienced by these groups. Whilst it is important to note when ethnicity and SES impact health and health behaviours such as CRC screening, not all differences in ethnicity can be attributed to SES and vice versa, as will be argued in the next chapter (Atkin, Ali et al., 2009). The next chapter will also provide an overview of the main psychological factors that have been associated with the uptake of screening alongside an outline of the theoretical perspective underpinning this thesis.

## **2.12 The relationship between ethnicity, SES and screening uptake**

In light of the various definitions of ethnicity and SES discussed so far in this chapter, some of the possible mechanisms through which minority group membership and SES may impact the uptake of cancer screening will now be discussed.

In relation to ethnicity, some minority groups may lack English proficiency which may impact their ability to read and understand screening invitations and the accompanying information about the screening programme (Bartley 2004). Furthermore, different ethnic groups may have different religious or cultural beliefs about health, illness and prevention encompassing notions of what behaviours are acceptable and which are not, such as collecting a faecal sample. As mentioned briefly in an earlier section of this chapter, perceptions of racial discrimination may lead to mistrust of the health service and healthcare professionals which may also affect uptake of health services such as screening (Karlsen and Nazroo 2002). Such negative experiences may also undermine people's beliefs about the efficacy of screening as well as foster a sense of disenchantment and reluctance to consider decisions about their health (Karlsen and Nazroo 2002). Differences in family history of CRC and perceptions of CRC risk may be further contributory factors for particular ethnic groups, such as those with a known genetic vulnerability to CRC, such as Ashkenazi Jews (Cappelli, Hunter et al. 2002).

With regards to SES, links to uptake of CRC screening can be made to each of the indicators discussed earlier. 'Materialist' factors such as the lack of health insurance, difficulties with transport or being unable to take time off from work have been cited as barriers to uptake of screening by low SES individuals in the USA (Price 1993, James, Hall et al., 2008). For people earning a 'low' income, barriers to CRC screening may be more practical and relate to working patterns. For instance, screening could be deemed a low priority when working long or irregular hours. Another hindering factor to screening could be the perceived loss of income as a result of a cancer diagnosis. For countries that offer CRC screening via endoscopy, people may not feel they can, or be able to, take time off from work to attend clinic appointments. At present, screening and any subsequent care or treatment is free at the point of use in the UK. 'Freepost' envelopes are also sent along with FOBt kits to enable return. However, as noted by von Wagner et al., (2011), despite there being no monetary cost attached to CRC screening in the UK, socio-economic inequalities have still been found



to exist. This suggests that perhaps SES factors beyond income may influence people's decisions about CRC screening participation.

In relation to education, people with lower educational attainment and may have lower levels of knowledge about CRC and screening, especially about screening in the absence of symptoms or 'precancerous' changes (von Wagner et al., 2011). They may also have lower levels of literacy which may impact their ability to read, process and understand information about screening. Closely related to literacy is the concept of health literacy, that is people's ability to obtain, process and understand information about health and navigate health services (von Wagner, Semmler et al. 2009). People with lower health literacy may be less likely to engage with the perceived benefits of screening due to lack of awareness that cancer can be asymptomatic, for example (von Wager et al., 2011, von Wagner et al., 2009). Screening may also be a low priority for people with lower educational attainment, perhaps due to competing work related demands or other health problems. Educational attainment is also associated with an increased propensity to take control over one's life, increasing self-confidence and empowerment in future decisions (von Wager et al., 2011). Furthermore, higher educational attainment is also proposed to foster greater self-confidence and perceived control over one's own actions in averting negative health outcomes (von Wager et al., 2011). Higher educational attainment has also been linked to greater consideration of future consequences versus short-term benefits. In relation to screening, people who have a 'learned' tendency to consider and plan for the future may consider taking part in screening in order to mitigate problems associated with late diagnosis (Whitaker, Good et al. 2011).

The level of deprivation in individuals' neighbourhood environment may influence participation in screening in several ways. Firstly, as outlined earlier, there may be a dearth of health services in general in the area which may contribute to the lower awareness of screening (Weyers, Dragano et al. 2010). London in particular is known to have a highly mobile population and this may be a further possible explanation for low uptake rates if

people do not update addresses with healthcare providers (Logan, Patnick et al. 2012). In terms of housing, poorer quality housing has already been linked to greater co-morbidities, which may in turn affect how much individuals value screening amongst their other health concerns (Bartley 2004).

The proposed explanations discussed in this section strongly suggest that ethnic and SES factors do not operate independently. The consideration of SES factors when examining ethnic differences, and vice versa is profoundly important when trying to identify the determinants of health and health behaviours such as screening. The mechanisms outlined above also include many psychological factors such as knowledge, perceived benefits and perceived control that may mediate the social inequalities observed in the uptake of CRC screening. Indeed, a lot of research has studied the beliefs of different ethnic and SES groups about CRC screening; however there is a dearth of empirical evidence that has examined the mediators of ethnic and SES disparities in screening uptake. The systematic review in chapter four will address this point. Prior to that, the next chapter will outline the theoretical basis of this thesis and the commonly identified psychological factors that have been found to influence the uptake of screening.

# **Chapter Three**

## **Theoretical Framework**

### **3.1 Chapter overview**

The purpose of this chapter is to outline the theoretical perspective underpinning this thesis. This chapter is in three parts; the first part will discuss how screening is offered in the UK and the concept of informed choice, the second part of the chapter will use psychological theory to examine the factors that underpin people's decisions to participate in health behaviours such as screening, and how these factors translate into action. Lastly, the chapter will end with the rationale for choosing the theoretical framework adopted and how it will be used to address the objectives of this thesis.

### **3.2 Overview of screening**

Prior to commencing the discussion of the theoretical framework, this chapter will begin with a brief examination of the key facets of the behaviour of interest; participation in a population screening programme for colorectal cancer (CRC). Screening is an example of a preventive health behaviour; that is "any activity undertaken by individuals in order to prevent or detect illness at an asymptomatic stage" (Kasl and Cobb 1966, p.246). There are many features of the CRC screening programme that distinguish it from the other existing cancer screening programmes for breast and cervical cancer. Firstly, CRC screening is offered every two years through the self-completed Faecal Occult Blood test (FOBt). Completion of the test requires people to follow a set of instructions and may also require careful considerations for the handling and storage of the test kit as three separate stool samples are required across a two week period. Completed FOBt kits are then posted to the nearest regional screening centre where they are analysed. Aside from completion of the test

itself, participating in the CRC screening programme may incur additional consequences such as making further decisions regarding diagnostic tests (should they be indicated), the possibility of receiving bad news if disease is detected as well as any unnecessary worry caused by false positive results. Furthermore, the CRC screening programme is unique in that it is the first cancer screening programme in the UK to include men as well as women. In addition, there is no direct interaction with primary care or any health care professionals as screening is centrally organised. Therefore, participating in CRC screening can be deemed a novel, complex and infrequent behaviour given the meticulous process involved in completion of the FOBt, fairly long interval between each screening invitation and lack of dependence on healthcare professionals as is the case for other CRC screening tests such as flexible sigmoidoscopy.

The following section will discuss the way in which population screening is offered in the UK including a detailed examination of the concept of informed choice that underpins the ethos of current UK health policy on screening. The aim of this discussion regarding informed choice is to facilitate further understanding of how and why people from different social and ethnic groups make the decisions they do about participating in CRC screening.

### **3.3 Informed choice and screening**

Cancer screening has a history of being ingrained within public health policy that focuses on disease prevention at the population level. As noted by Marteau and Kinmonth (2002), the traditional public health approach to screening is concerned with maximising uptake of screening rather than informed participation. Moreover, the public health approach focuses on benefits to the general population and thus fails to consider the potential harms of screening such as complications arising from screen detected abnormalities, over detection and unnecessary worry (Irwig, McCaffery et al. 2006). The establishment of formal breast and cervical cancer screening programmes in the mid 1980's was based on the public health

principle and as such, screening was promoted as a beneficial, preventative activity in which all eligible women should participate (Forrest 1987). However, there has been considerable debate surrounding the existence and extent of population benefits in recent years (Independent UK Panel on Breast Cancer Screening 2012). The last two decades have seen a strong shift towards a policy of informed patient consent, control and respect of autonomy across a range of healthcare choices surrounding treatment, participation in medical research, and screening (Jepson, Hewison et al. 2007). The expression “informed choice” is preferred to “informed consent” when referring to health screening because people are usually invited to participate and can choose whether to do so or not. Furthermore, as argued by Jepson, Hewison et al., (2005) “informed consent” implies more active decision making following some level of contact or discussion with a health professional thus it may not be relevant to CRC screening as direct interaction with health professionals is minimal, or non-existent for the many people who receive a ‘normal’ result. Informed choices have been defined as those that are ‘based on relevant knowledge, consistent with the decision maker’s values and behaviourally implemented’ (Marteau, Dormandy et al. 2001).

Informed choice is now considered alongside other more conventional requirements of a screening programme such as quality assurance, and improvements in survival (Wilson and Jungner 1968, Andermann, Blancquaert et al. 2008), as illustrated in the following excerpt from the second report of the National Screening Committee that oversees screening programmes in the UK;

*“There is a responsibility to ensure that people who accept an invitation do so on the basis of informed choice, and appreciate that in accepting an invitation or participating in a programme to reduce their risk of an adverse outcome.” (National Screening Committee 2000)*

Similar recommendations are made by the General Medical Council (GMC), the professional regulatory body for doctors in the UK (General Medical Council 2008). Guidance from the GMC proposes several key facets of information should be given to enable people to make an informed choice about whether or not to participate in screening. These include information on the purpose of screening, the likelihood of positive/negative findings, the possibility of false positive/negative results, uncertainties and risks attached to the screening process, whether there are any significant medical, social or financial implications of taking part in screening and, availability of follow-up support services (General Medical Council 2008). Therefore, giving people sufficient and balanced information about possible risks and lack of certainty regarding the benefits of screening is paramount to the philosophy of informed choice.

As well as being part of the drive for openness and transparency within the NHS, a policy of informed choice reflects awareness that it is unethical for people not to be fully informed about what screening can and cannot achieve (Irwig, McCaffery et al. 2006). Screening differs from clinical practice in an important way as it seeks to identify a disease or a condition at an early stage or asymptomatic stage, prior to seeking medical advice (Skrabanek 1990). One can argue that to some extent, screening resembles a population level experiment given that a large number of apparently healthy individuals need to be screened in order to identify a relatively small number of people who have pre-clinical disease (Skrabanek 1990). For example, screening via FOBt is predicted to reduce CRC mortality by approximately 1 death per 1,000 people screened over 10 years (Scholefield, Moss et al., 2002). Therefore, people invited for CRC screening must balance this relatively small potential benefit against the potential harms associated with participating. Although there are no direct harms associated with the FOBt, screening may trigger a medical trajectory that healthy persons may not have otherwise undergone; for instance the occurrence of a false positive result and follow-up by colonoscopy which involves a risk, albeit small, of perforating the bowel and, in extreme cases, death.

## **Understanding informed choices**

As established earlier in this chapter, informed choices about whether or not to undergo screening are those based on good knowledge, consistent with the individual's attitudes and behaviourally implemented (Marteau, Dormandy et al. 2001). Accordingly, two factors thus impede individuals from making an informed choice: firstly lack of knowledge and secondly, a failure to act in concordance with attitudes, together leading to an uninformed choice. Attitudes do not necessarily need to be positive in order to make an informed choice as consistency between attitudes and behaviour, supported by good knowledge, is the crux of informed choice. Where individuals have a negative attitude towards screening, are well informed and do not participate, they are still considered to be making an informed choice (Marteau, Dormandy et al. 2001). As discussed in chapter two, uptake of CRC screening is variable and particularly low in certain ethnic minority and socially deprived groups. However, it is presently unclear whether, and to what extent, people from varying backgrounds and socio-economic situations hold different attitudes or, are more or less likely to act consistently with their attitudes about CRC screening. Further unpacking and exploration of this issue is the aim of the systematic review in chapter four. Research in the context of prenatal screening for Down's syndrome revealed that low uptake of screening in South Asian and socioeconomically disadvantaged women reflected lower rates informed choice due to low levels of knowledge rather than more negative attitudes towards screening (Dormandy, Michie et al. 2005). Moreover, the inconsistency between attitudes and behaviour was more pronounced for women who held positive attitudes towards prenatal screening for Down's syndrome although the authors were not able to identify the cause of this inconsistency (Dormandy, Michie et al., 2005).

Good knowledge is another component of informed choice. Individuals need to be able to read and understand the information presented to them, weigh up the different options and carry out their intended choice. However, reading and appraising information in this way

may be a potential barrier for people with low literacy skills. Furthermore, Fox, (2006) argued that screening programmes should not solely rely on providing written information to invitees in order to promote informed choice following her review of randomised control trials pertaining to informed choice. The review identified nine trials across a range of screening programmes, finding that whilst written information increased knowledge in the majority of studies, an increase in knowledge was associated with attitude change in only one study (Fox 2006). More recently, in an analogue study examining the impact of informed choice invitations on uptake of diabetic screening (Mann, Kellar et al. 2010), again knowledge was found to be a weak predictor of people's intentions to undergo screening ( $\beta=.13$ ,  $p=.005$ ), whereas attitude emerged as a strong predictor ( $\beta=.64$ ,  $p=.001$ ).

Aside from attitudes and knowledge, another key component of several health behaviour theories is behavioural intention, or a plan to undertake behaviour. With regards to screening, intention towards undergoing screening is known to be an overall strong predictor of uptake, with a medium sized relationship (pooled effect size reported as 0.42; Cooke and French, 2008). However, as reported by Mann, Kellar et al., (2010), intentions to undergo diabetes screening were much higher than actual uptake of screening. Further understanding of the intention-behaviour relationship and reasons that may underpin the gulf between the two will be covered later in this chapter. Despite being well-informed, having positive attitudes and intentions to undergo screening, many people still do not participate in screening and thus their behaviour may not actually reflect their initial choice. A multitude of factors may be underpinning this difference between screening choice and screening behaviour.

Recent research has focused on identifying some of the reasons why people may or may not take part in CRC screening. Overall, reported barriers include lack of awareness of screening (Maxwell, Bastani et al. 2011), low perceived risk due to lack of symptoms, lack of time, disgust at the idea of handling faecal matter (Chapple, Ziebland et al. 2008), embarrassment



(Brenes and Paskett 2000), fatalistic beliefs (Power, Van Jaarsveld et al. 2008), fear of the outcomes of screening (Austin, Power et al. 2009) and lack of general practitioner recommendation to take part (Chapple, Ziebland et al., 2008).

Understanding why people decline or accept the offer of a screening test for CRC is an important practical question given the implementation of a national CRC screening programme. There are also important psychological questions as to what factors different people take into account when reaching their decisions. Why and under what conditions do people take action? Does low uptake of CRC screening indeed reflect how people value screening and its potential outcomes, or a failure to make an informed choice? These questions will be addressed as the thesis progresses. Prior to that, the next section focuses on psychological theory and how it may be used as a starting point for examining the aforementioned questions.

### **3.4 Selection of theoretical approach**

Theory is defined as;

*“A set of interrelated concepts, definitions, and propositions that present a systematic view of events or situations by specifying relationships between the variables in order to explain and predict events or situations” (Glanz, Rimer et al. 2008), p26).*

According to the aforementioned definition, theories or models of health behaviour should thus identify the constructs (the component parts of theories) that explain behaviour, the relationships or interactions between the constructs and how these may vary across different situations, contexts, populations and behaviours. Being able to predict behaviour using theory allows us to develop explanations and work towards devising behaviour change

interventions by targeting determinants, specified by the theory, that are potentially amenable to change. This is particularly important in the context of this thesis as one of the purposes is to explain the varied patterns evident in uptake of CRC screening and identify potential strategies to facilitate informed choices in screening uptake. Therefore, the theory used in this thesis needs to be able to model how people think about participating in CRC screening and help identify areas for intervention, alongside allowing consideration of the role of informed choice.

There is growing emphasis for behavioural interventions to be based on and guided by theories of health behaviour (Michie, Johnston et al. 2005). Use of theory is also advised as the first step in the Medical Research Council's (MRC) published guidance for the development and evaluation of complex interventions (Craig, Dieppe et al. 2008). In the first step, evidence to support the theoretical basis of an intervention is gathered. In the second step, known as modelling, the behavioural determinants to be targeted and the techniques that can be used to change these factors are identified. Thus, theory is integral to the planning, implementation and evaluation of behavioural interventions (Lippke and Ziegelmann 2008). From a practical point of view, application of theory helps to explicitly identify the mechanisms that are hypothesised to underlie behaviour change and importantly, whether an intervention actually produces the desired change in behaviour (Lippke and Ziegelmann 2008). If an intervention does not work or works in other ways than those expected, i.e. in a way not explainable within the theoretical framework, a review of the theory alongside the techniques employed to change behaviour would be required.

As mentioned above, many different factors are likely to contribute to the development, maintenance, and change of health behaviours. Although research has demonstrated CRC screening uptake varies by socio-demographic factors such as ethnicity and socioeconomic status (as well as age and gender), these variables can rarely be changed by an intervention. For this reason, we turn to evidence relating to factors that are modifiable – people's beliefs

about a particular behaviour, also known as health cognitions. These cognitions can be instrumental or affective in nature; the former referring to cognitive aspects of completing the behaviour and the latter reflecting emotional drivers of behaviour. Collectively, health cognitions are assumed to mediate the relationship between socio-demographic factors and health related behaviours such as screening (Conner 2010). We already have a sense from the preceding discussion that acting in accordance to one's values and attitudes is important when determining what constitutes as an informed choice. Therefore, it is reasonable to examine how such values and other beliefs determine behaviour as well.

### **3.6 The social cognition approach to understanding health behaviour**

A plethora of psychosocial theories, collectively known as social cognition models (SCMs), have added to our understanding of how cognitions and social factors contribute to determine health behaviour. Different combinations of these factors are featured in the theories and there is much overlap of constructs across the various theories and models. SCMs advocate that behaviour is best understood by examining people's thoughts or cognitions about the behaviour in a social context, and their social perceptions and representations (Rutter and Quine 2002). Social cognition models (SCM) of health behaviour can also be considered part of the self-regulation tradition, as individuals are involved in the modification of their own behaviour through goal setting, undertaking cognitive preparations and ongoing monitoring of goal-directed activities (Conner and Norman 2005). Thus SCMs attempt to place people within the context of both other people and the broader social world. Although most theories focus on the individual, inclusion of social cognitive factors provides a strong rationale for using the SCM approach. Social cognitive factors reflect the enduring characteristics of individuals that are acquired through the socialisation process and help to shape behaviour (Conner and Norman, 2005). Furthermore, the relative importance of each of the social-cognitive factors is postulated to

vary as a function of both the behaviour and the population being studied (Fishbein 2000). Thus, the SCM approach allows comparisons to be made between individuals of the same and varying backgrounds, for example when examining the attitudes and beliefs of people from different ethnic and/or socioeconomic groups; comparisons that will be undertaken through the qualitative and quantitative studies (chapters five and six, respectively).

Gollwitzer (1993) distinguished two phases of behaviour; the motivational and the volitional. In the motivational phase, individuals decide which goals to pursue following deliberation on the incentives and expectations associated with the behaviour. Subsequently, the volitional phase involves planning and action of the set goals towards behaviour change (Conner and Norman, 2005). This motivation–volition distinction is useful for studying the intention-behaviour gap in screening uptake described earlier as the intentions formed in the motivational phase may not always get translated into action. Furthermore, different factors may be significant in the motivational phase than in the volitional or action phase. However, as will be demonstrated in the subsequent section, the majority of SCMs focus on the motivational phase although research is increasingly focusing on the volitional phase of action.

When selecting a theoretical approach to understand a behaviour, it is important to ensure the theory is relevant to the behaviour being studied and the purpose of studying it. It is also parsimonious to assume that most types of health behaviour are influenced by a similar set of determinants (Sutton 2004). However, currently no single theory or conceptual framework dominates research on understanding people's health behaviours, including decisions about, and uptake of, screening. Nevertheless, reviews of research on a broad range of health behaviours have indicated a trend in theory use (Glanz, Rimer et al. 2008, Painter, Borba et al. 2008). In reviews of theory use in published research between 1999 and 2005, the most commonly used theories were the Transtheoretical Model (TTM), Social Cognitive Theory (SCT) and Health Belief Model (HBM), the Theory of Reasoned Action

(TRA) and its successor the Theory of Planned Behaviour (TPB), stress and coping, approaches focusing on social support/social networks, ecological models and the diffusion of innovations (Painter, Borber et al., 2008). In an earlier review by Glanz, Lewis et al., (1996), five main theories were found to dominate the field in journal articles published approximately 10 years earlier, between mid-1992 to mid 1994. The theories included the HBM, SCT and its self-efficacy construct, the TRA/TPB, the TTM and social support/social networks (Glanz et al., 1996). Overall, it is evident that the same few theories appear to be dominating research, with little change over the last two decades or so despite dozens of theories and models being available (Glanz and Bishop 2010). To provide the context for the theoretical perspective chosen for this thesis, the following section will briefly outline the central tenets of four of the most prominent health behaviour theories and models; the HBM, TPB, SCT and TTM, alongside a discussion of their potential utility in this thesis.

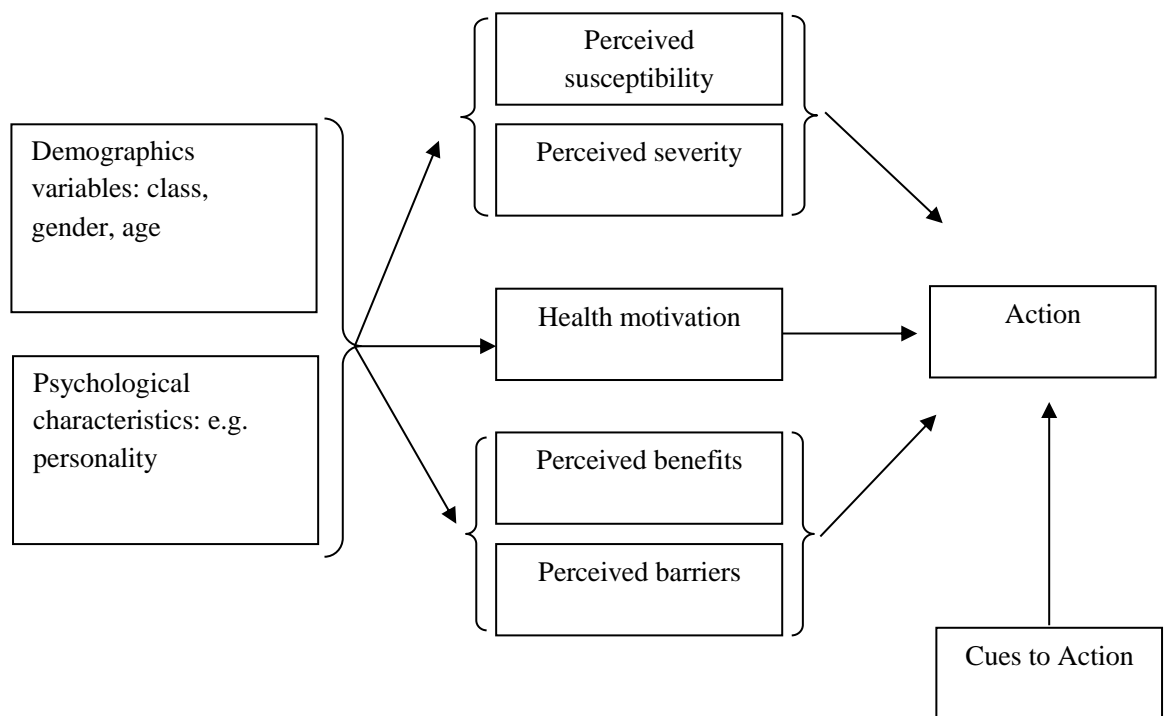
### **3.7 Individual theories and their key constructs**

#### **3.7.1 Health Belief Model (HBM)**

The HBM (Rosenstock 1966) was one of the first theories of the determinants of health behaviour. Originally, the HBM was developed to help understand why people did not use preventive services offered by public health departments, such as x-rays as part of tuberculosis screening (Hochbaum 1958). The HBM is displayed in figure 3.1, page 62. Two main types of cognitions are proposed to underpin behaviour; perceptions about disease threat and a belief, or behavioural evaluation, that adopting a particular health behaviour will mitigate that threat (Abraham and Sheeran 2005). Perceptions about the disease threat consist of beliefs regarding perceived susceptibility, one's chances of getting a condition, and perceived severity which relates to perceptions about the seriousness of the condition and its sequelae. Behavioural evaluation also consists of two beliefs; consideration of the perceived benefits of, and costs or barriers to, undertaking the health behaviour. Thus, according to the HBM, the decision to undergo a CRC screening in the absence of any

symptoms will not be made until an individual feels they are likely to develop CRC, believes there will be serious consequences resulting from a CRC diagnosis, and the benefits of taking part outweigh the perceived costs, e.g. the belief that early detection of CRC will lead to successful treatment despite the unpleasantness of the test. Furthermore, the test itself must be perceived as feasible, appropriate to complete and not hindered by any psychological barriers (Abraham and Sheeran, 2005). On the other hand, an individual who believes their risk of developing CRC is low, believes that taking part in screening will not reduce their risk, and perceives the costs of participating in screening to outweigh the benefits, may choose not to participate in screening. The model also argues that behavioural action is facilitated by cues to perform the test, such as receipt of a screening invitation, perceiving a bodily state or from interpersonal interaction. A further more general and stable construct is also postulated to directly influence behaviour. Known as health motivation, this refers to how much individuals value their health and, their propensity to look after it (Abraham and Sheeran, 2005). Individuals with high health motivation would therefore be more likely to participate in screening as screening allows an opportunity to monitor and keep check on their health.

The HBM was gradually revised to include the construct of self-efficacy (not shown in figure 3.1) which refers to people's confidence in their ability to perform a behaviour, such as completion of the FOBt. This extended HBM version with the addition of the self-efficacy construct has been found to improve the general predictive power of the model (Rosenstock, Strecher et al. 1988). However, as noted by Abraham and Sheeran, (2005), when people were overly confident about their ability to complete a behaviour, known as the ceiling effect, or unconfident, known as the floor effect, self-efficacy may not always enhance the predictive capacity of the model. As well as being a standalone construct, self-efficacy may also be reflected within one of the existing constructs such as perceived barriers. Moreover, self-efficacy has been found to be a strong predictor of behaviour and also features in the remaining theories discussed later in this section.



**Figure 3.1:** *The Health Belief Model (source: Abraham and Sheeran 2005)*

### Utility of the HBM for understanding screening behaviour

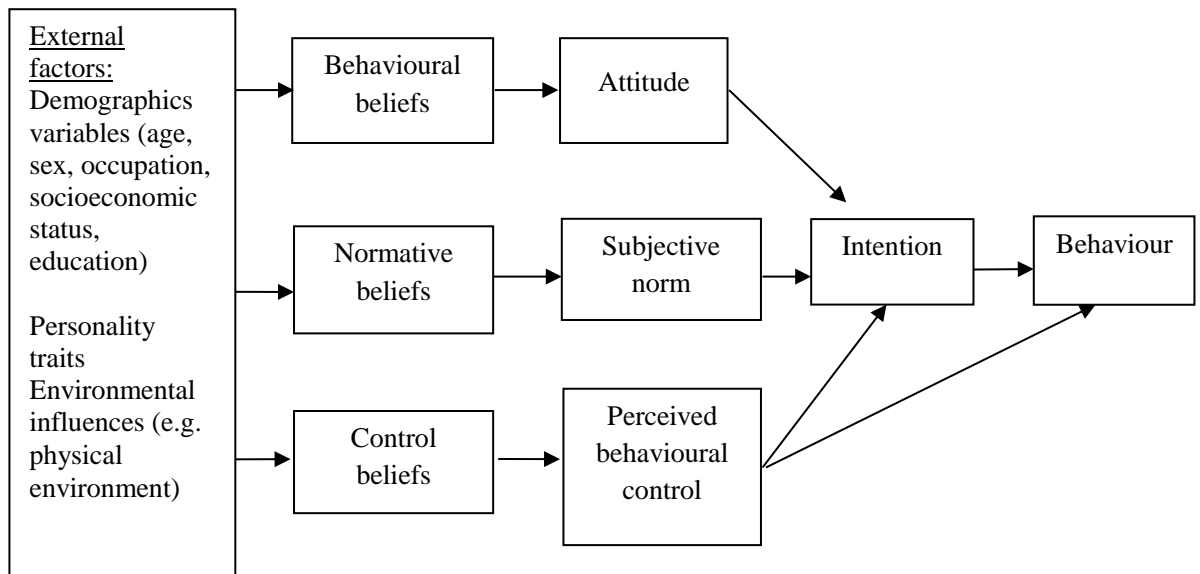
The HBM has been widely utilised to help understand participation in a range of health screening behaviours. However, there are a number of difficulties compromising the utility of the HBM as the majority of research only focuses on four factors; the threat (perceived severity and susceptibility) and behavioural evaluation (perceived barriers and benefits) constructs, while health motivation and cues to action are seldom scrutinised. In a review of the quantitative reviews of the HBM, Abraham and Sheeran, (2005) reported that whilst the four factors were often found to be statistically significant predictors of health-related behaviours, effect sizes tended to be small, implying heterogeneity of study designs and measures, as well as in the operationalisation of constructs. In relation to CRC screening, Power, Van Jaarsveld et al., (2008) found that whilst perceived severity, susceptibility, benefits and barriers were all significantly related to intentions to participate in screening via flexible sigmoidoscopy, they were not associated with uptake of the behaviour. Moreover, as

noted by Yarbrough and Braden, (2001), the HBM does not consistently predict breast cancer screening behaviour due to shortcomings including the lack of clarity in the definitions of each construct, their boundaries and the factors that influence the constructs. Furthermore, the relationship between the constructs have not been well validated and many studies focus on only linear relationships between the factors rather than exploring potentially multiplicative, interactive influences of the constructs on one another (Yarbrough and Braden 2001).

### **3.7.2 Theory Planned Behaviour (TPB)**

The TPB (Ajzen 1991) originated in the realm of social psychology and has been applied to help understand a variety of other behaviours as well as those relating to health. According to the TPB, as displayed overleaf in figure 3.2, one proximal determinant of behaviour is the intention to perform the behaviour itself. Behavioural intention is determined by three constructs; one's overall attitude towards a behaviour; referring to beliefs about how favourable or unfavourable the behaviour in question is, perceived social pressure to perform a behaviour and motivation to comply with social norms, known as subjective norms, and perceived behavioural control (PBC); which refers to perceptions of personal control over executing a behaviour. PBC is postulated to predict behaviour both directly and indirectly, mediated through intention (Ajzen, 1991). According to Ajzen, when people's perceptions of control match their actual control over behaviour, PBC should also predict actual performance of the behaviour. PBC has been operationalised in a number of ways: often considered in terms of perceived confidence in one's own ability to perform the behaviour (similar to the concept of self-efficacy described earlier), as well as reflecting control beliefs regarding the presence of obstacles, skills, resources and opportunities that may facilitate or hinder performance of behaviour.





**Figure 3.2:** *The Theory of Planned Behaviour (source: Conner and Norman, 2005)*

According to the TPB, an individual will form a positive intention to participate in CRC screening if they perceive screening as a behaviour with positive outcomes (e.g. reassurance about one's health), believe their significant others (e.g. spouse, friends) will want them to participate and perceive themselves as being capable to complete the FOBt. Fluctuation in intentions to participate in screening as well as performance of the behaviour may also be affected by beliefs about control, for instance, in the presence of any perceived barriers such as difficulties understanding the instructions for FOBt completion.

The majority of research applying the TPB tends to focus on the relationship between intention and behaviour as intention has been found to consistently, although moderately, predict the enactment of many health behaviours including screening (Armitage and Conner 2001). Furthermore, as depicted in figure 3.2, the TPB also assumes background factors such as socio-demographics are distal, or far removed predictors that are mediated by the more proximal predictors of intention and behaviour (Conner and Norman, 2005). TPB proposes that these background factors underlie attitudes, subjective norms and PBC whereby people with different life circumstances, e.g. SES, may have different levels of accessible beliefs

that vary in content. For instance, people from higher SES backgrounds may be able to recall a greater number of advantages related to participation in CRC screening compared to people from lower SES backgrounds. However, research has found a direct and unmediated influence of such background factors on intentions and behaviour, and this is inconsistent with the tenets of TPB (Sutton 2004). In relation to CRC screening via flexible sigmoidoscopy, some variation in attitudes across the socioeconomic gradient has been demonstrated where negative, pessimistic and fearful attitudes have been found to be common in lower socioeconomic status and less educated groups (McCaffery, Wardle et al. 2003)

### **Utility of TPB for understanding screening behaviour**

The TPB provides a strong framework to understand people's motivations for behaviour and action. It has been widely applied to a range of health behaviours, including screening and several studies have investigated the relationships between the TPB constructs and behaviour. Cooke and French (2008) conducted a meta-analysis to examine the efficacy of TPB to predict attendance at a range of screening programmes. Three studies relating to CRC screening were included in the meta-analysis of 33 studies and overall demonstrated medium effect sizes for the attitude-intention relationship ( $r=.43$ ), and intention-behaviour relationship ( $r=.44$ ). However, large effect sizes were found for the subjective-norm-intention relationship ( $r=.52$ ) and PBC-intention relationship ( $r=.62$ ) in relation to CRC screening. These findings may reflect intricacies related to the nature of behaviour as all three studies on CRC screening included the FOBt. The strong subjective norm intention relationship may reflect a social aspect of the behaviour where individuals look for approval or encouragement from their significant others. On the other hand, the strong PBC-intention relationship may be due to the self-completed aspect of the behaviour whereby the onus is on individuals to perform the behaviour. Therefore, greater capability barriers to self-completed tests such as the FOBt may be perceived compared to hospital based procedures

such as flexible sigmoidoscopy. Furthermore, a number of variables were found to moderate relationships between all the TPB variables such as, type of screening test, receipt of a screening invitation and whether the screening test is free (Cooke and French, 2008). For example, attitudes were more strongly associated with intentions when screening was offered by GPs, whereas intention predicted uptake of screening best when screening was offered in hospital settings. This finding has potential implications for the UK CRC screening programme which is currently offered independently to primary and secondary health services.

A more recent meta-analysis on the efficacy of the TPB by McEachan, Conner et al., (2011) found that type of behaviour studied moderated the predictive capacity of the theory. Behaviours such as screening fall under the category of detection behaviours and were overall found to be poorly predicted, with variance explained ranging from 13.8-15.3%. Furthermore, the variance explained in overall behaviour was almost half of the variance explained in intention (19.3% vs. 44.3%). However, in support of the assumptions of TPB, intention demonstrated the strongest relationship with prospective behaviour with a medium-to-large effect size (mean  $r=.43$ ) and attitude emerged as the strongest predictor of intentions (mean  $r=.57$ ). Most strikingly however, past behaviour was found to be the overall strongest predictor of behaviour, greater than intention, although it is not usually included as a traditional TPB variable (McEachan, Conner et al., (2011).

### **3.7.3 Social Cognitive Theory (SCT)**

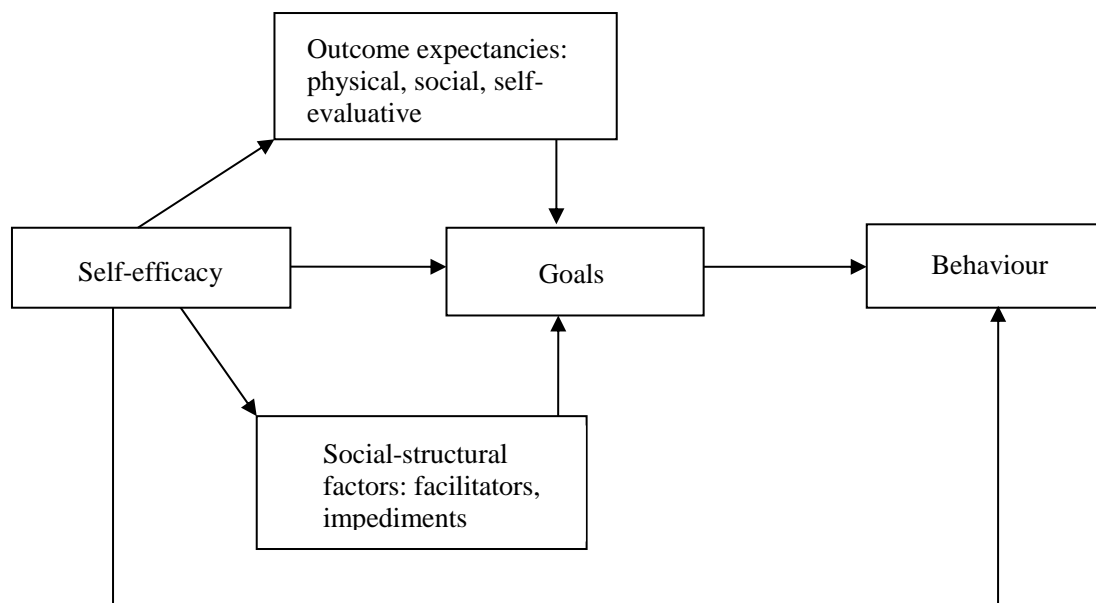
The theories discussed so far are primarily focused on the individual. However, the enactment of health behaviours may often be impeded by environmental or social barriers such as access to healthcare services. A theory that goes beyond individual level factors and considers the role of environmental and social factors in the regulation of behaviour is SCT (Bandura 1986). Figure 3.3, page 68, depicts SCT in its current form. According to SCT,

three main factors determine behaviour; goals, outcome expectancies and self efficacy. The three main factors are supposed to operate through a continuous, dynamic interaction between the person, their environment and behaviour, also known as reciprocal determinism (Bandura, 1986). Thus, through this reciprocal relationship, behaviour exerts an influence on both the environment and the person as well as being influenced by them (Redding, Rossi et al. 2000). In SCT, goals are conceptualised as plans to act and can be likened to intentions to perform the behaviour as in the TPB. Outcome expectancies are beliefs about the likelihood, and value of, the consequences of behavioural choices. Although outcome expectancies are quite similar to behavioural beliefs in the TPB, they are further separated into physical, social and self-evaluative, depending on the types of outcomes being considered (Conner, 2010). Social outcome expectancies can be likened to the concept of subjective norm in TPB and reflect individuals' expectations of how different people will evaluate their behaviour as well as their own willingness to be guided by others. Self-evaluative outcome expectancies however, are an anticipation of how individuals will feel about themselves following behavioural action.

SCT was the first theory to include self-efficacy, which has since been incorporated as an additional component of several health behaviour theories including the HBM and TPB. Self-efficacy includes beliefs about how much a behaviour is under an individual's control, assessed as the degree of confidence an individual has in their capabilities to perform a behaviour in the face of any obstacles or barriers (Conner, 2010). Different types of factors can influence a person's self-efficacy, including persuasion by others, observing the behaviour of others and previous experience of performing the behaviour as well as physiological arousal and affective states (Bandura 1997).

SCT was revised to include socio-structural factors, referring to impediments to, or facilitators of behaviour that are associated with broader facets of life including living conditions, economic and environmental, as well as health and political systems (Bandura

2000). It is assumed that these social-cultural factors inform goal setting and are also influenced by self-efficacy. More specifically, self-efficacy is supposed to influence social-cultural factors by impacting individuals' propensity to pay attention to opportunities or impediments in their life circumstances. People with higher self efficacy are more likely to pay attention to life opportunities whereas those with lower self-efficacy are less likely to pay attention to life opportunities (Conner, 2010).



**Figure 3.3:** *Social Cognitive Theory (source Conner, 2010)*

In relation to CRC screening, SCT would propose that an individual is more likely to participate if: 1) they plan to complete the test, 2) feel confident that they can complete the FOBt and 3) believe there will be positive consequences as a result of undergoing screening e.g. feeling reassured about their health following a negative result. Moreover, goals or plans for FOBt completion are influenced by an individual's confidence in their ability to overcome any barriers relating to completion of the test e.g. handling of a faecal sample and if screening is recommended by a significant individual e.g. spouse or GP, who persuades them that screening is a good idea.

### **Utility of SCT for understanding screening behaviour**

SCT has been applied to understand a range of detection behaviours although most studies only focus the construct of self-efficacy and full applications of the theory are scarce (Conner 2010). Nevertheless, self-efficacy has been found to be strongly related to uptake of CRC and other cancer detection behaviours such as breast self-examination (Meyerowitz and Chaiken 1987) and prostate cancer screening in first-degree relatives (Cormier, Kwan et al. 2002). In the latter study, self-efficacy and outcome expectancies were stronger predictors of uptake of prostate cancer screening than factors including doctor recommendation, knowledge and risk perceptions. Several studies have demonstrated the importance of self-efficacy in relation to CRC cancer screening whereby high levels of self-efficacy are predictive of uptake of screening and low levels are a barrier. Self-efficacy is also related to factors such as health literacy that may be a potential barrier to screening uptake. von Wagner, Semmler et al., (2009) found that lower health literacy, as well as being related to lower levels of information seeking and greater perceived effort of reading, was also associated with lower self-efficacy for FOBt completion. These findings have implications for understanding the uptake of CRC screening in groups with lower educational attainment. Individuals may struggle to read and understand information regarding the advantages and risks of participating in screening alongside difficulties comprehending the instructions for FOBt completion, which in turn may impact their confidence and perceived ability to complete the test.

#### **3.7.4 Transtheoretical Model (TTM)**

The final model to be outlined is the TTM (Prochaska and Velicer 1997). The TTM is a stage model of behaviour change and assumes adoption of health behaviours, such as screening, requires individuals to pass through four distinct stages. The stages in the TTM are pre-contemplation; when an individual is not thinking about change e.g. taking part in

screening, contemplation; when an individual is aware for the need for behaviour change and is considering whether to participate, preparation; where an intention to change behaviour in the near future has been made and action is taken to prepare for the change, and finally action of the behaviour (Conner 2010). There is also a fifth stage, maintenance of behaviour, however it is not relevant here as screening is a relatively infrequent behaviour. Although progress through the stages is assumed to be sequential, the TTM does allow for regression to earlier stages as many times as are required prior to behaviour action, should an individual not successfully pass through a stage the first time (Sniehotta and Augner 2010). Furthermore, the stages of change can be utilised to help understand when shifts in attitudes, intentions and behaviour will occur. However, as noted by Armitage and Conner (2000), there is very little indication about how such changes occur.

The TTM also features the following additional constructs: decisional balance, self-efficacy and temptation. Decisional balance refers involves consideration of the pros and cons of carrying out the behaviour e.g. early detection of CRC. Self-efficacy is conceptualised in a similar manner as in the models previously discussed and relates to situation specific confidence in performing a behaviour such as the FOBt. Finally, temptation can be viewed as the reverse of self-efficacy and reflects urges to engage in a specific behaviour (usually unhealthy) during a difficult situation, for example as a result of emotional distress (Glanz et al., 2008). Furthermore, the TTM also hypothesises there are ten independent experiential and behavioural processes of change that facilitate transitions between the stages.

### **Utility of the TTM in understanding screening behaviour**

Despite its intuitive appeal, the TTM has received many criticisms as empirical studies have found little evidence that people progress from stage to stage, in the order specified, and that interventions targeting specific stages are more successful than those that do not target stages (Sniehotta and Augner, 2010). Furthermore, the stages themselves have been deemed

to be arbitrary in nature and do not map onto the different psychological processes they have been speculated to so do (Sniehotta and Augner, 2010). However, despite these criticisms the TTM has been a popular theory for studying uptake of CRC screening. In a study by Menon, Belue et al., (2007) where the TTM was used as a foundation for intervention development, differences between stages were found according to type of screening test. More specifically, in relation to FOBt and sigmoidoscopy, more people were found to be in the pre-contemplation stage. Individuals in the pre-contemplation stage also had lower perceived risk than those in the contemplation stage, lower perceived benefits than those in the action stage, and higher barriers than both those in the contemplation and action stages (Menon, Belue et al., 2007). However, in a systematic review on the effectiveness of TTM interventions for different health behaviours, support for the overall model was weak in evidence drawn from stage matched and mismatched studies (Littell and Girvin 2002).

### **3.8 Which theory to use?**

Given the number of theories and, in turn, numerous proposed determinants that are available to researchers, it becomes difficult to choose the most relevant, appropriate and inclusive theory to investigate a given behaviour. There are also several other potentially relevant health behaviour theories that were not discussed in the previous section including Protection Motivation Theory (PMT; Rogers 1975), the Health Action Process Approach (HAPA; Schwarzer 1992) and the Precaution Adoption Process Model (PAPM; Weinstein and Sandman 2002). It would not be feasible or practical to use all the potentially relevant theories. However, currently there is also a lack of systematic basis for selecting a single theory to use (Francis, Stockton et al. 2009). Researchers have thus tended to base investigations of health behaviours on a small number of constructs, despite the opportunity to access a definitive and more comprehensive set of theoretical explanations to identify which particular explanation is relevant to particular health behaviours (Michie, Johnston et al. 2005). The majority of SCM models and theories include some common factors that are



widely believed to be important to behavioural regulation and change (Noar, Chabot et al. 2008). Moreover, studies purportedly applying the different theories rarely examine all of the constructs and often focus on single constructs or a constellation of few constructs as a substitute for the whole theory (Kiviniemi, Bennett et al. 2011).

Overall, however, there is consensus that attitudes, social influence, intention, perceived risk or susceptibility and PBC, which is also conceptualised as self-efficacy, are significant determinants of behaviour, although differing terms are sometimes used for the same or similar concepts so they appear to be separate (Noar et al., 2008). For instance, it is questionable whether benefits and barriers, attitudes, positive and negative expectancies and pros and cons, are really that different from one another. If the constructs appearing in different theories are indeed the same, continuous overlooking of this issue by researchers will result in a fragmented literature, unless some consensus is achieved and attempts at integration are made. Weinstein (1993) notes there are some key differences in how similar theoretical constructs are conceptualised e.g. whether self-efficacy should be distinguished from other types of barriers, either real or perceived. Even similar conceptualisations of the same constructs such as fear arousal, perceived susceptibility or self-efficacy need to be closely and critically examined to identify their underlying dimensions and determine whether they really are the same or different.

Although there is a high degree of overlap between constructs across the various theories, exclusion of key behavioural determinants by individual theories contributes to the gap between intentions and performance of behaviour (Noar et al., 2008). Additionally, there are many other factors that influence behaviour that are not incorporated in any single theory. For instance, behaviour or the perceived need for action are not only influenced by perceived likelihood and severity but also factors such as how vivid any harm of non-action is to the person, the frequency of reminders, availability of cognitive resources such as memory, any sensory experiences associated with the 'hazard'/behaviour, impulsive reactions, social

meaning of the behaviour as well as the part of the body affected, which may all influence behaviour (Weinstein, 1993). Other issues, such as familiarity or novelty of the behaviour, may also be relevant for understanding factors underlying decisions to act (Weinstein, 1993). Such non-cognitive influences also include the role of past behaviour and habit. As found in the pilot evaluations of the CRC screening programme, people who previously participated in screening were more likely to participate at their next screening invitation two years later, reflecting the importance of past behaviour when repetition, albeit infrequent, of the behaviour is required, (Weller, Coleman et al. 2007).

A common thread through all of the SCMs discussed above is the assumption that health behaviours occur as a result of reasoned, intentional and conscious processes of the expectancy and value of potential health threats and possible coping responses. Apart from reasoned attitudes, goals and intentions, non-deliberative, hedonic and impulsive processes may also play an integral role in the enactment of health behaviour. They include ambivalence and emotional/affective beliefs, and are not included in the theories outlined above, although research has found factors such as fear of cancer can be a strong barrier to undergoing screening (Austin et al., 2009). However, following the acknowledgement of the importance of emotions, affective beliefs have now been included in the TPB.

Emotion has traditionally been viewed as an impediment to effective decision making, either as a distraction or a source of bias. However, emotions are now considered very much critical components of sense-making and action through processes such as ‘affective-forecasting’ that use simulations of future experiences as the basis for present actions e.g. anticipated regret of behaviour performance or non-performance. However, a key criticism of SCMs, including the aforementioned models, is the failure to explicitly consider the role of affective influences on behaviour despite awareness of their importance (Conner, 2010). Furthermore, Loewenstein, Weber et al., (2001) distinguished between understanding information about risk, such as that contained in informed choice screening invitations, at a

cognitive level (risk as analysis) and the affective reactions such information generates, ‘risk as feelings’. This latter ‘risk as feelings’ hypothesis proposes that decision making surrounding risk can have affective consequences in the form of worry, fear or anxiety. Moreover, these affective responses can also influence individuals’ cognitive evaluations of risk and factors that do not enter into cognitive evaluation, such as immediacy of the risk (Loewenstein, Weber et al., 2001).

Aside from fear, evidence is growing on the role of other emotions. More recent work by Curtis, de Barra et al. (2011) on the emotion of disgust has revealed some interesting nuances about the construct; particularly relevant for understanding completion of the FOBt because it requires handling of faecal matter. Disgust has been reported to be a type of ‘moral emotion’ that helps people decide what is right and what is wrong (Curtis et al., 2011). It is seen as based on an adaptive system to counteract disease threat and is proposed to vary by individuals’ personality, learning experience as well as cultural influences and norms surrounding manners and purity (Curtis et al., 2011). With regards to the FOBt, research has found that, universally, people find faecal matter disgusting (Curtis et al., 2011). Handling human faeces has connotations of disease, contamination and shame, where sense of smell can be a powerful trigger. Although people’s disgust sensitivity may vary, the emotion of disgust can induce powerful affective and behavioural responses for some and thus lead to the rejection of CRC screening via FOBt, as demonstrated in several studies (Chapple et al., 2008, Friedemann-Sánchez, Griffin et al. 2007), James, Hall et al. 2008). Furthermore, disgust may be evaluated as a potential psychological cost of completing the FOBt and reflect a way of self-policing one’s hygiene and social behaviour. Therefore, despite being traditionally viewed as irrational processes, emotions may in fact guide behaviour in a more systematic, adaptive or maladaptive manner.

At this point it is also useful to draw on the work of Strack and Deutsch, (2004), which has helped to further reconcile the influence of cognitive and affective behavioural determinants.

Strack and Deutsch's two-system model contends that behaviour is a joint function of the reflective and impulsive processes. The reflective system is proposed to elicit behaviour as a consequence of a decision process following appraisal of knowledge, value and probability of potential consequences (Strack and Deutsch 2004). Contrastingly, behaviour generated through the impulsive system is based on the activation of associated clusters of the perceptual aspects of a phenomena or behaviour that are stored in long-term memory. These are known as behavioural schemata and are created, stored and strengthened gradually over time by an individual's experiences (Strack and Deutsch 2004). For example, repeated experience with health care services may lead to the formation of an associative cluster that connects this experience with negative affect and the behavioural schema that has led to the negative affect (experience with health services). Furthermore, Strack and Deutsch, (2004) stipulate that these impulsive processes operate in an effortless, automatic manner, for example when acting in the "heat of the moment". Thus the reflective deliberative model integrates elements from existing health behaviour models such as perceived consequences, with mental processes, and behaviour (Strack and Deutsch 2004).

In relation to CRC screening, decisions to participate that are based on the perception that screening would be beneficial for oneself may be driven by reflective deliberation on the consequences of screening participation. On the other hand, affective associations with faecal matter based on learning and culture, such as disgust, may trigger more impulsive, automatic processes that are unaccompanied by conscious reflection, thus leading to the rejection of screening via the FOBt (Curtis, de Barra et al. 2011). Furthermore, people may also vary in their ability to undertake reflective, deliberative processing which may contribute to any SES inequalities in screening uptake. As discussed in chapter two, people of low SES are more likely to have lower educational attainment and due to their socio-economic position, may also experience greater chronic stress (Grundy and Holt, 2001). Collectively this may be cognitively taxing and individuals may find themselves juggling competing tasks and demands, thus allowing less room for deliberative thought (Marteau,

Hollands et al. 2012). Therefore, interventions targeted towards automatic processes may have the potential to reduce health inequalities because they do not rely on individuals' literacy, numeracy and ability to comprehend complex information regarding a particular behaviour, which are generally poorer in those who are more socially deprived (Marteau, Hollands et al., 2012). In this way, it may be more useful to view health behaviours as occurring as the result of several different types of determinants that operate in harmony or conflict with one another where certain factors promote more reflective behaviours whereas others promote more automatic behaviours (Marteau, Hollands et al. 2012).

### **3.9 Methodological issues to consider when applying SCMs**

There are a number of key methodological issues and limitations arising from research using the social-cognition approach that may be potentially relevant to the present research and these will be discussed next. Firstly, although we study health beliefs as a means to understand and change behaviour, it may be possible that the beliefs that change behaviour are different to the beliefs that predict it. The SCMs discussed above do not account for this. Moreover, whilst the theories aim to identify which beliefs determine behaviour, there is very little explicit guidance on how these beliefs should be targeted and changed, with the exception of SCT and TTM that do outline some techniques through which behaviour can be altered.

Problems with the measurement of social-cognitive variables may also help explain the intention-behaviour gap as well understand the reasons why SCMs have been found to have lower predictive power than would be preferred. These problems include the lack of correspondence of measures with behaviour, random measurement error in measures and use of different response categories. In addition, Sutton (2004) noted that the dichotomisation of behaviour as either completed or not is problematic for theories such as the TPB as it does not specify how intention, usually measured as a continuous variable, translates into a binary

outcome i.e. behaviour action or non-action. Furthermore, dichotomisation of behaviour in this way also neglects those who may have attempted the behaviour but did not successfully complete it, such as those who attempt to complete the FOBt but do not manage to return the test kit.

As well as identifying which beliefs are salient, attention also needs to be directed at the reasons behind people's beliefs, such as the reasons behind people's negative attitudes, rather than descriptions of the attitudes per se. Aside from the motivational influences on behaviour, recent research attention has focused the volitional phase of action through constructs such as implementation intentions (Gollwitzer, 1993). Implementation intentions refer to specific if-then plans that specify performance of the behaviour subject to specific environmental conditions e.g. "I plan to complete the first day of the FOBt on Thursday morning, in my bathroom, prior to having a shower". Formation of implementation intentions has been found to increase the performance of many health behaviours, with on average, a medium effect size (Conner, 2010). Furthermore, implementation intentions have been found to moderate the intention-behaviour relationship, particularly for individuals with strong goal intentions. They have also been found to be helpful for overcoming memory lapses that may prevent the performance of some behaviours (Conner, 2010).

As argued by Sutton, (2004), research needs to go beyond the mere prediction of behaviour and move towards explanation of the causal processes of behavioural enactment. Using within-individuals, longitudinal designs where repeated measures of cognitions and behaviour are taken over multiple time points, is one way of gauging the causal effects of SCM constructs (Sutton, 2004). In order to change behaviour, we need to first understand the mechanisms through which behaviour is enacted. The identified factors should then be manipulated in randomised experiments to test their influence (Sutton, 2004). However, studies using cross-sectional designs that provide a post-hoc explanation of behaviour are still commonplace and provide very little beyond a description of the behaviour (Sutton, 2004). Furthermore, intention is often used in studies not only as a predictor but also as an

outcome, and many studies do not even measure behaviour. Intentions however, cannot and should not be substituted for behaviour (Weinstein and Rothman 2005). If they were interchangeable, then intentions would explain the majority of the variance in behaviour and there would be no intention-behaviour gap that is so often reported in research.

Most studies rely on self-report measures of behaviour, which are known to be heavily distorted by recall and social desirability biases. It is likely that using more objective measures may allow for better prediction of behaviour as opposed to behaviour assessment through self-report measures. The quantitative study undertaken as part of this thesis will address the issues raised by adopting a prospective design with objective measurement of behaviour and examine the potential causal processes between ethnicity, SES, psychological factors and behaviour through mediation analysis.

### **3.10 The theoretical framework of this thesis**

It is apparent from the preceding discussion that many different factors determine behaviour but are not all captured by any individual theory, although there is much overlap between constructs in the various SCMs. Despite the limitations outlined in the previous section, health behaviour theories have remained remarkably similar over the last fifteen years with little revision and there is a paucity of studies comparing and testing different theories. One way of taking a more inclusive approach to selecting theory was demonstrated by Michie, Johnston et al., (2005) who identified a comprehensive set of twelve theoretical domains. The Theoretical Domains Framework (TDF) was developed using a consensus approach with three groups of experts including health psychologists, health services researchers and healthcare professionals. It was originally developed to study healthcare professionals' behaviour, specifically implementation of evidence based practice. Six stages were involved in the development of the TDF (Michie et al., 2005).

These included:

1. Identification of theories and theoretical constructs
2. Simplification of the constructs into theoretical domains
3. Evaluation of the importance of the theoretical domains
4. Interdisciplinary evaluation of the theoretical domains
5. Validation of the domain list
6. Pilot of the TDF interview questions generated

The first three stages were completed by a group of 18 UK health psychologists, interested in the implementation of evidence based practice and behaviour change. Through a brainstorming session in the initial meeting, the group identified as many psychological theories and constructs that were as relevant as possible to the behaviour of interest, implementation of evidence based practice. The theories and constructs themselves were derived from theories concerned with motivation, action or volition as well as those concerned with behaviour change at a higher order social and systems level (Michie et al., 2005). In the second step, the identified theories and constructs were independently grouped into core domains which comprised a similar set of constructs. Consensus on which domains were to be retained was reached following discussion and comparisons of the generated domains. Each theory and construct identified in stage 1 was then allocated to the agreed list of domains. Constructs were retained in the domain they were assigned to if they were also assigned to that domain by at least half the group members. The list of theoretical domains was then independently evaluated in the third step for coherence, any overlap in constructs and to identify any relevant constructs that had been missed earlier. In the fourth step, the theoretical domains were evaluated by health service researchers for usefulness in evaluating behaviour change interventions. In step five, a group of 30 healthcare professionals participated in a 'backward validation' of the list of domains whereby they identified theories and constructs that were relevant to the content of the domains. Finally, both health



psychologists and health service researchers generated and piloted interview questions based on the theoretical domains to identify the domains relevant to understanding behaviour change for the behaviour of interest. The consensus approach outlined above identified 128 constructs across 33 theories that were mapped onto twelve theoretical domains. Details and definitions of the included theoretical domains and the constructs they map onto are given in table 3.1, below.

**Table 3.1:** *The Theoretical Domains Framework (TDF; adapted from Michie et al., 2005)*

<b>Domain</b>	<b>Definition</b>	<b>Construct</b>
Knowledge	An awareness of the existence of something.	Knowledge about colorectal cancer, symptoms Knowledge of screening programme
Skills*	An ability or proficiency acquired through practice	Competence/ability
Social role and identity*	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting.	Identity Religious/cultural identity Social/group norms
Beliefs about capabilities*	Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use.	Self-efficacy Control over behaviour Perceived competence Self-confidence Perceived behavioural control Optimism/pessimism Empowerment
Beliefs about consequences*	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation.	Outcome expectancies (physical, social, emotional) Anticipated regret Consequences Rewards/benefits Perceived risk/threat Negative consequences
Motivation and goals*	The outcomes or end states to which one is striving and a person's willingness to exert physical or mental effort in pursuit of those outcomes or end states.	Intention (stability and certainty) Goals Goal priority Intrinsic motivation Commitment Distal and proximal goals Incentive to participate

Memory, attention and decision processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives.	Memory Decision making Attention Familiarity of the behaviour
Environmental context and resources*	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour.	Resources/material resources (availability and management) Environmental stressors
Social influences*	Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours.	Social support Social pressure Feedback Social comparisons Social norms
Emotion*	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event.	Affect (positive or negative) Stress Anticipated regret Fear Threat (of cancer) Anxiety/worry
Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions.	Goal/target setting Implementation intention Action planning Goal priority Barriers and facilitators
Nature of the behaviour	Essential characteristics of the behaviour.	Routine Nature of proposed behaviour Context Representation of tasks

With the aim of providing the most comprehensive explanation of CRC screening uptake, the theoretical domains identified by Michie et al., (2005) will form the basis of the present thesis. The TDF was selected as the theoretical approach for this thesis following an appraisal of the various theories discussed earlier and, in light of the findings from further examination of the individual constructs of the theories.

There are several advantages of using the TDF: firstly it includes a comprehensive set of constructs to help capture the range of mechanisms that may be playing a part in behaviour (change) such as those that are internal (psychological) as well as external influences such as the environment; presenting an important step forward in moving towards an explanation of behaviour. Secondly, the independent generation of the domains and consensus approach adopted also adds validity to the approach. Furthermore, bringing together researchers and practitioners not only gives access to the vast knowledge base of these experts, but also includes the perspective of those dealing with the behaviour, in this case, implementing evidence based practice, on a daily basis; adding further validity and authenticity to the domains elicited. More pertinently however, using the TDF will allow the examination of a comprehensive list of psychological determinants of CRC screening for different ethnic minority and SES groups to help ascertain whether low uptake of CRC screening reflects an informed choice not to participate, or whether psychosocial barriers hinder uptake for those who would otherwise want to be screened. In addition, a further strength of the TDF is the inclusion of domains that are relevant to the concept of informed choice discussed earlier in this chapter.

Aside from the TDF, there have been other attempts of integrating psychological theories. A similar attempt was undertaken by Fishbein, Triandis et al., (2001) in the realm of HIV prevention behaviours. The integrated theories included the TPB's predecessor the Theory of Reasoned Action, SCT, HBM, Self-regulation (Kanfer and Kanfer 1991) and Theory of Interpersonal Behaviour (Triandis 1977). Following a theorists' workshop in 1991, an integrated model of behaviour was proposed which stated that any given behaviour is more likely to occur if: a person has a strong intention, has the necessary skills and abilities to perform the behaviour and environmental restrictions are not hindering behaviour enactment (Fishbein et al., 2001). The constructs featured in Fishbein et al.'s 2001 integrative model are very similar to those included in the TDF, with the remaining constructs in the integrated model being viewed as determinants of intention strength. Overlapping domains from the

work of Fishbein et al., (2001) in relation to the TDF are asterisked in table 3.1. Additionally, there are four other domains in the TDF that were not included in Fishbein et al.'s model including knowledge, memory, attention and decision processes, and behavioural regulation. Michie et al., (2005) speculated that identification of the extra domains may reflect wider expertise of the participants in their group as well as developments in the behaviour change literature in the time since the work of Fishbein et al., (2001). Nevertheless, the high overlap of domains across both groups provides further validation for the constructs included in the TDF.

Both Michie et al., (2005) and Fishbein et al., (2001) advocated the need for greater precision in the description and definition of the behaviour of study in order to identify and explain the underlying processes alongside possibilities for change. The need for more precise definitions of behaviour relates back to a point discussed earlier in this chapter; that different determinants may underpin different behaviours. This was illustrated in a cross-sectional study by Grispen, Ronda et al., (2011) that examined the psychological determinants of a range of self-completed tests for glucose, cholesterol and HIV and although FOBt was not included in the study, the results may be relevant to this thesis due to the self-completed nature of the test. The theories included were HBM, TPB and PMT and analysis of survey data revealed that greater perceived benefits and self-efficacy were significantly associated with self-completing all three tests. However, the importance of determinants including perceived susceptibility, subjective norm and moral obligation appeared to be more test specific. For instance, subjective norm, the belief that one's partner would expect them to do the test, was a significant predictor of cholesterol screening but not HIV or glucose testing. On the other hand, moral obligation and perceived susceptibility were significant predictors of both cholesterol and HIV screening but not glucose screening (Grispen et al., 2011). These findings suggest the need to tailor interventions to specific tests rather than the overall behaviour type, e.g. self-completed tests, as well as reinforcing

Michie et al's (2005) and Fishbein et al.'s, (2001) recommendations to increase focus on the nature of individual behaviours.

The research presented in this thesis is the first application, to our knowledge, of the TDF to understanding screening as a health behaviour and specifically uptake of CRC screening. Previous applications of the framework have been concerned with healthcare professionals and implementing behaviour change on a clinical or professional level (Dyson, Lawton et al. 2011; hospital staff hand hygiene, Francis et al., 2009; physician's transfusion practice and Bonetti, Johnston et al. 2010; dental guidelines in Scotland). However, despite the breadth and comprehensive coverage of theoretical constructs, the TDF remains underused. Nevertheless, there are some limitations of using the TDF that must be considered prior to its use. The framework does not specify the relationships between the included theoretical constructs and is thus not a substitution for a theory. Francis et al., (2009) used the domains identified through the TDF to select relevant theories to predict physician's transfusion behaviour. Similarly, the TDF can be used to identify the techniques for behaviour change for determinants in particular domains, such as in the recently developed 'Behaviour Change Wheel' (Michie, van Stralen et al. 2011) although how best to elaborate and operationalise the framework remains unclear (Francis, O'Connor et al. 2012). The TDF was developed to understand a specific behaviour, implementation of evidence based practice which is very different to uptake of CRC screening by the public. Therefore, a flexible approach will be adopted in this thesis when applying the TDF to understand uptake of CRC screening as additional factors that influence CRC screening uptake may be relevant that are currently not included in the TDF.

Since Michie et al's original publication of the TDF in 2005, there had been little validation of the framework until a recently conducted study by (Cane, O'Connor et al. 2012). A similar procedure to that used to devise the initial TDF was employed where behavioural theory experts sorted 112 unique theoretical constructs firstly into groups of their choice (open sort

task), and secondly into domains defined in the original framework (closed sort task). Discriminant Content Validation and Fuzzy Cluster analysis tested the extent of replication with the structure and content of the original framework with the results leading to refinement of the framework. A total of 14 domains are included in the validated TDF rather than 12 domains that comprised the original TDF and are listed below. The 'Nature of Behaviour' domain was removed entirely as the original component constructs of this domain were not assigned to it in the closed sort task. Further changes included the separation of the 'Motivation and Goals' domain into two domains: 'Intentions' and 'Goals' where the former equates to a conscious decision to perform behaviour and the latter refers to an end state such as a preferred outcome (Cane et al., 2012). The 'Beliefs about Consequences' domain was also separated into two domains, one retaining the original name and the other named 'Reinforcement', where the former refers to beliefs whereas the latter focuses on associative learning through rewards or punishment. Lastly, the 'Beliefs about Capabilities' domain was also separated into two domains where one retained the original name and included beliefs about specific capabilities required to perform a behaviour, and the other was named 'Optimism' to incorporate individuals' general disposition.

**Domains in the revised, validated version of the TDF (Cane et al., 2012):**

1. 'Knowledge'
2. 'Skills'
3. 'Social/Professional Role and Identity'
4. 'Beliefs about Capabilities'
5. 'Beliefs about Consequences'
6. 'Emotions'
7. 'Social Influences'
8. 'Behavioural Regulation'
9. 'Memory, Attention and Decision Processes'

10. 'Environmental Context and Resources'
11. 'Optimism'
12. 'Reinforcement'
13. 'Intentions'
14. 'Goals'

Some limitations of the newly validated TDF must be considered. Firstly, there were a number of constructs that appeared in multiple domains, such as 'Action Planning', which was found in both the 'Goals' and 'Behavioural Regulation' domains, indicating a possible lack of precision of the boundaries between domains. Secondly, as noted by Cane et al., (2012), the refined framework is very much dependent on the constructs that were identified in the original framework and as such, does not include all behaviour change theories so important constructs may be missing.

### **3.11 Role of theory in this thesis**

Following recommendations by the MRC (Craig, Dieppe et al. 2008) and calls for more theory-based interventions (Michie, Johnston et al. 2008), the TDF will be employed in this thesis, forming the theoretical basis of the empirical research that is reported in the subsequent chapters. As data had already been collected for the studies in this thesis prior to publication of the revised validated version of the TDF (Cane et al., 2012), the un-validated original version of the TDF was utilised (Michie et al., 2005). In chapter four, theory will be used to identify the social patterning of TDF constructs in different ethnic minority and SES groups through a systematic review. The validated TDF was incorporated in the systematic review where findings have been organised according to the refined domains. Chapter five reports a qualitative study in which a theory based interview schedule, based on the TDF, is used to explore the salient factors affecting participation in CRC screening by ethnicity and SES in the target population of South East London. The beliefs elicited through the

qualitative study inform the development of a questionnaire that will quantitatively examine which beliefs are the best predictors of CRC screening uptake in a prospective study; chapter six. Finally, based on the findings of the empirical research and in line with the aims of using theory that were set out at the beginning of this chapter, strategies for enhancing informed choices in screening uptake will be outlined in the conclusion chapter.



# Chapter Four

## Systematic Review

### Abstract

**Aims:** To systematically examine the literature regarding linkages between ethnicity, socio-economic status (SES) and psycho-social constructs in relation to CRC screening and examine the patterning of beliefs about CRC screening via FOBt in different ethnic minority and socio-economic groups.

**Methods:** A comprehensive search was undertaken to identify papers that examined the beliefs about CRC screening via the FOBt of various ethnic minority and/or socio-economic groups. Papers were synthesised using narrative synthesis (Popay et al., 2006) and results were structured according to the newly validated version of the Theoretical Domains Framework (TDF; Cane et al., 2012).

**Results:** A total of sixteen papers were included in the review of which eight studies employed quantitative methods, seven studies employed qualitative methods and one study employed a mixed design. Findings of the narrative synthesis indicated that many beliefs relating to theoretical domains including knowledge, beliefs about consequences, emotions, social influence about CRC screening were shared by ethnic minority groups from the UK, USA and Australia. Papers regarding SES found that people of lower SES tended to have lower knowledge of CRC screening, were more fatalistic and more likely to report problems with misunderstanding the instructions for FOBt completion. Papers that examined beliefs according to both ethnicity and SES predominantly demonstrated complex relationship between ethnicity and SES but mainly comprised ethnic minority groups of low SES.

**Conclusion:** This review has outlined some interesting patterns in the beliefs about CRC screening in different ethnic and socio-economic groups. Such patterning may help understand low uptake of CRC screening in an ethnically and socio-economically diverse area of south east London. However, studies were limited in their consideration of both ethnicity and SES factors as well as an explicit theoretical basis.

## 4.1 Introduction

A wealth of research has examined the psychological and socio-demographic predictors of CRC screening uptake. As outlined in chapter two, evaluations of the first and second rounds of the CRC screening programme showed that uptake of the Faecal Occult Blood test (FOBt) was low in individuals of South Asian origin as well as those who lived in areas of high deprivation (Weller et al., 2007). From the discussion in the previous chapter, it is also evident that psychological factors such as embarrassment, fear of outcomes, negative attitudes and fatalism can negatively influence people's intentions and behaviour regarding CRC screening.

Numerous individual studies that focus on CRC screening in relation to differing ethnic and/or SES groups and various psycho-social constructs are available. However, there is currently no systematic overview or clarity about how ethnicity and/or SES factors are related to the psycho-social constructs that may in turn, influence the uptake of screening. This review is a novel attempt to systematically examine the linkages between ethnicity, SES and psycho-social constructs in relation to CRC screening. It is possible that members of different ethnic groups have different beliefs about cancer and its prevention, and this may affect their decisions about screening. Also, those experiencing economic disadvantage may have certain beliefs or encounter additional barriers that hinder their ability to make an informed choice about CRC screening participation. There is, however, a lack of consolidation of how specific psychological factors, that theories of behaviour suggest are important for determining intentions for and uptake of CRC screening, vary in different ethnic and SES groups; a gap that will be bridged by this review.

To our knowledge, this systematic review is also the first to consider ethnicity and SES together. The majority of studies regarding the patterning of beliefs about CRC screening tend to focus on ethnicity and SES individually and potentially risk attributing differences to

ethnicity that might actually be due to SES variation between ethnic groups, or vice versa. The inclusion of both ethnicity and SES in this review will help identify where such misattributions might be made.

The validated Theoretical Domains Framework (TDF) will be used to structure the findings from this review (Cane et al., 2012). Featuring throughout this thesis, the TDF includes a comprehensive coverage of the possible psychological determinants of health behaviours, including uptake of CRC screening. Use of the TDF in this chapter is underpinned by the objective to consolidate the numerous psychological factors that have been linked to uptake of CRC screening.

Using a structured theoretical framework and method of synthesis, the findings from this review have the potential to move the social inequalities field forward and contribute to the development of intervention strategies to facilitate informed choices about CRC screening (see chapter seven). The findings will explore whether SES and ethnicity may affect participation in screening through their impact on specific psychological constructs. Identified relationships will inform the analysis of the empirical research in chapters five and six (qualitative interviews and questionnaire survey, respectively) and also highlight any gaps in the literature that can be addressed through the present research.

#### **4.1.2 Aim of review**

The aim of this review is to synthesise and critically review research regarding the socio-demographic patterning of beliefs about CRC screening across several prominent psychological theoretical domains.

## **4.2 Methods**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher, Liberati et al. 2009) guidelines were followed in conducting this systematic review in order to facilitate the comprehensive reporting of the relevant aspects of the review.

### **4.2.1 Data sources and searches**

The systematic search process involved five main steps. Firstly, a search strategy comprising of terms for each part of the question was developed: (Colorectal) + (cancer) + (screening) + (screening tests) + (psychosocial variables) + (ethnic minority groups) AND/OR (SES). The full search terms that were used for each electronic database are included in appendix 4.1. Secondly, electronic database searches were performed across the following databases: ISI Web of Science, Scopus (which includes Medline and EMBASE), CINAHL, ASSIA, and PSYCINFO from inception to 14<sup>th</sup> November 2011. Thirdly, the reference lists of all papers that met the inclusion criteria were manually searched and citation searches were performed to identify any further relevant papers. In addition, to help identify literature that was not published in peer reviewed journals, the NHS National Research Register (NRR) archive, the website of the National Cancer Action Team (<http://www.cancerinfo.nhs.uk>) and the Open Grey website (<http://www.opengrey.eu>) were each searched for reports of research commissioned by the Department of Health, research on cancer and grey literature in Europe, respectively. Finally, alerts were set up for each of the bibliographic databases searched to September 2012 to identify any new papers since the searches had been conducted.

#### **4.2.2 Study selection**

Titles and abstracts of each obtained reference were initially scanned for relevance by the author and PhD supervisor (AJW). Papers that referred to CRC screening, ethnic groups and/or socioeconomic groups as well as psychological theory or specific constructs, were retained for appraisal of full texts. Full text papers were then obtained for studies deemed relevant at this stage and were appraised against the inclusion-exclusion criteria. A random sample of 10% of the full text papers were double coded with respect to inclusion or exclusion by the author's supervisor (AJW). The following criteria were applied to appraise papers:

##### *I. Types of determinant*

Papers reporting psychological factors: (intention, subjective norm, outcome expectancy, self-efficacy, knowledge, emotions (fear, anticipated regret, embarrassment, disgust) attitudes, health beliefs, perceived behavioural control, perceived risk and consequences) in relation to socioeconomic factors (including education, income, area deprivation and health insurance status (where applicable), and/or ethnic minority group status, were included. Studies that focused only on the predictors of screening uptake were not eligible for inclusion in this review as the focus was on the patterning of psychological beliefs in different groups. Potential predictors of screening uptake are outlined in chapter three and will be examined in the questionnaire survey reported in chapter six.

Quantitative papers were required to present the data separately for different ethnic minority/SES groups, where included, and qualitative studies were also required to make explicit comparisons if multiple ethnic groups were included. For papers that did not include separate group information, corresponding authors were contacted to request this data, if it was available.

## *II. Screening tests*

Initially, papers concerning all types of CRC screening tests such as the FOBt, flexible sigmoidoscopy and colonoscopy, were included, as reflected in the search strategy. However, due to the distinctive self-completed nature of the FOBt that sets it apart from other clinic based screening tests such as flexible sigmoidoscopy, the focus of this review was later limited to the FOBt only.

## *III. Participants*

Participants who were members of any ethnic minority group in any country were included. However, papers that focused exclusively on majority group populations were not included as one focus of the review was to explore beliefs in relation to minority group status. Similarly, for papers examining SES patterning, participants from either a range of SES backgrounds or low SES were required in order for the paper to be included in this review. Study participants were also required to be within the age range for CRC screening in their respective countries in order for studies to be relevant to this review.

## *IV. Study design*

All study designs were eligible for consideration in the review as long as primary data was reported. Quantitative and qualitative studies were equally eligible for inclusion as the method of synthesis allowed studies of different designs to be compared.

Studies were excluded if they:

- I. Did not examine patterning of psychological beliefs by ethnicity, SES or both.
- II. Examined other screening tests apart from FOBt

- III. Were commentaries or review papers; although the latter were used to identify additional papers for inclusion in this review.
- IV. Were only development or validation studies of scales measuring health beliefs in relation to CRC screening.
- V. Were CRC screening cost effectiveness studies
- VI. Considered screening only for cancers other than CRC
- VII. Explored the general experiences of cancer patients except those where patients' retrospective CRC screening experience was explored.
- VIII. Focused only on the predictors of screening uptake

#### **4.2.3 Data extraction**

Full-text papers were imported into the Nvivo data management programme (QSR International Pty Ltd; Doncaster, Victoria, Australia) and data were extracted from relevant studies. A framework matrix was created in Nvivo to tabulate the extracted data. For electronic formats of papers that could not be uploaded into Nvivo, relevant data were hand typed into the matrix. Once more, data from a 10% random sample of papers was independently extracted by the author's supervisor (AJW) to verify accuracy and completeness of data extraction. Information relating to the following variables was extracted from each study and coded in Nvivo:

- Bibliographic information
- Country of origin
- Study aims and objectives
- Study recruitment procedure including how participants were identified, recruited and allocated to groups (where applicable)
- Participant characteristics – to include number of participants, ethnicity and/or SES, age, gender, education, risk status, income, health insurance status (where

applicable) and any other relevant information (e.g. number of years resident in country).

- Number of participants in each ethnic or SES group
- CRC screening test(s) of interest
- Study design
- Method of data collection
- Psychological determinants/theories studied
- Description of statistical or qualitative data analysis method
- Main findings to include findings and comparisons in relation to the psychological variables and demographic factors

#### **4.2.4 Quality assessment**

Due to the heterogeneity of methods used within the identified studies, a validated quality assessment tool developed by Sirriyeh, Lawton et al., (2011), was utilised as it allowed comparison of the quality of quantitative, qualitative and mixed methods studies. This tool facilitates assessment of the robustness of study design and methods; reference to theory; sample size and representativeness; any validation of measures; the extent of user involvement; and evidence of critical discussion and limitations. The full quality assessment criteria are included in appendix 4.2. Studies were rated against a total of sixteen criteria, of which fourteen criteria applied to qualitative papers only, fourteen applied to quantitative papers only and the full sixteen applied to mixed methods papers. Thus, there were twelve criteria that were common across quantitative and qualitative papers with two additional criteria that were unique to quantitative studies and two criteria that were unique to qualitative studies. Each criterion carried a quality score ranging from 0 to 3 where 0 denoted no evidence of coverage of the quality criterion and 3 denoted 'complete' coverage. The maximum quality score for qualitative and quantitative papers was 42 and, 48 for mixed methods papers. Total scores were converted into percentages allowing comparisons to be



made across studies using different methods. Although quality scores were not used to exclude studies from the review, they were considered when interpreting the findings of the synthesis.

#### **4.2.5i Data synthesis strategy selection**

A number of synthesis methods were considered prior to the selection of the narrative synthesis approach. Meta-analysis was not possible due to the number of qualitative studies that were relevant to this review and also due to the reporting of heterogeneous statistics in the quantitative studies, hindering effect size calculations. However, statistical heterogeneity was not the only reason why a meta-analysis was not undertaken. The papers included in this review were not only diverse methodologically but, also included a diverse range of ethnic groups that were described differently by different authors e.g. “Black”, “Non-White”, or “African American”. Furthermore, studies often used different conceptualisations of SES such as level of education or household income that tap into different aspects of SES are SES, as discussed in chapter two. In addition, studies also varied in the terminology used to describe apparently similar psychological constructs such as ‘knowledge’, ‘awareness’ and ‘understanding’. Thus, combining studies that were dissimilar methodologically and conceptually in a meta-analysis may have limited the validity of this review.

Below, three further methods of data synthesis including meta-ethnography, thematic synthesis and narrative synthesis are considered prior to outlining the data synthesis method employed in this review.

#### **4.2.5ii Meta-ethnography**

Meta-ethnography is an interpretive approach that was originally developed by (Noblit and Hare 1988) for combining the findings of ethnographic research conducted in the field of

education. It is now a common method of synthesising qualitative health research. The aim of meta-ethnography is to reach an overall interpretation that is greater than that offered by the individual studies included in the synthesis (Britten and Pope 2011).

Noblit and Hare, (1988) have outlined seven phases of a synthesis based on meta-ethnography. The first stage involves identification of the research question and establishing the rationale of the review. In the second stage, researchers decide what is relevant through development of search strategies, undertaking the searches themselves and selecting relevant papers. The third stage involves extracting key concepts from papers and using these as “data” following the repeated reading of papers. In the fourth stage, researchers explore relationships between individual studies by grouping papers. The fifth stage is an iterative process where each concept from each paper is “translated” or compared with all the other papers. In the sixth stage, these translations or comparisons are synthesised to examine the relationships between concepts, and the final stage involves expression of the synthesis in a textual form.

Using meta-ethnography may help provide a higher level of analysis, generate new research questions and reduce the duplication of research (Jones 2004). However, there are some key limitations that also warrant attention. Firstly, there is no guidance on how studies should be sampled and appraised (Dixon-Woods, Bonas et al. 2006). Moreover, it is also unclear how data saturation is determined in a meta-ethnography synthesis, where access to the original data is limited. Furthermore, context is central to the credibility of qualitative research whereby any synthesis should aim to retain the rich context of the data. However, as noted by Atkins, Lewin et al., (2008) contextual factors such as socio-economic status are poorly reported in papers. The approach of meta-ethnography is also challenged in retaining contextual authenticity of the primary data. One way of circumventing this issue is by firstly examining only studies undertaken in a particular context; but this may constrain the synthesis process of qualitative research further (Dixon-Woods, Bonas et al. 2006). As meta-

ethnography is only relevant for synthesising qualitative research, this approach is not suitable for synthesising the results of the present review.

#### **4.2.5iii Thematic synthesis**

Thematic synthesis (Thomas and Harden 2008) was developed primarily for the synthesis of qualitative studies that examine people's perspectives and experiences. This method builds upon some of the principles of meta-ethnography, described above, as well as grounded theory (Glaser and Strauss 1967), a commonly used method for analysing primary qualitative data. In a thematic synthesis, the raw "data" comprise verbatim text that is extracted from published study reports, typically labelled as 'results' or findings' by authors (Thomas and Harden 2008). There are three main stages in conducting a thematic synthesis. The first stage involves line-by-line coding of the extracted data, the second stage involves the development of "descriptive themes", and finally, the third stage involves the generation and comparison of analytical themes to identify the common themes across studies (Thomas and Harden 2008). The latter stage can also be likened to the sixth stage of meta-ethnography where concepts are translated across studies. The first two stages of a thematic synthesis can be seen as being inductive as the findings of the individual studies are analysed without any direct reference to the research questions of the review. However, the research questions are pivotal in the third stage where the analytical themes are generated, compared and synthesised across studies.

An advantage of thematic synthesis is the potential to draw conclusions based on common elements across otherwise heterogeneous studies (Lucas, Baird et al. 2007). Moreover, conclusions derived from a thematic synthesis can fulfil an important research aim of qualitative research in generating hypotheses, an area to which traditional systematic reviews are poorly suited (Barnett-Page and Thomas 2009). However, there is also a danger that pooling findings in a thematic synthesis risks masking the shortcomings of the

individual studies included in the review (Lucas et al., 2007). Although descriptions of study characteristics and quality appraisal are presented alongside synthesised findings, the synthesis process may obscure these in the conclusions. In light of these criticisms, thematic synthesis will not be utilised in the present review.

#### **4.2.5iv Narrative synthesis**

Textual narrative synthesis, referred to as narrative synthesis, (Popay, Roberts et al. 2006) is an approach in which studies are typically arranged into more homogenous groups. Narrative synthesis involves the reporting of study characteristics, context, quality and findings in a standard manner, allowing similarities and differences to be compared across studies (Popay et al., 2006). This technique has been particularly successful in synthesising different types of research evidence including qualitative, quantitative and economic studies (Lucas et al., 2007). Furthermore, narrative synthesis has been shown to help identify gaps in the literature by highlighting where evidence was absent and, by evaluating the strength of the evidence in different areas (Lucas et al., 2007). However, transparency of the narrative synthesis method has been questioned as it is not clear how sub-groups of studies should be established (Lucas et al., 2007). In the present review, studies can be grouped to explore beliefs about CRC screening in relation to the demographic factors of interest: ethnicity and socio-economic status. In a comparison of results from a thematic synthesis and a narrative synthesis, Lucas et al., (2007) found that compared to thematic synthesis, narrative synthesis was less good at identifying commonalities across studies but, was a better method for identifying heterogeneity between studies. Reviewers must therefore provide as much detail as possible about the method for carrying out a narrative synthesis in order to avoid criticisms regarding lack of transparency and validity.

Essentially, the type of synthesis to be used depends very much on the aims of the synthesis. If the aim is to generate hypotheses for future research then a thematic approach may be

more appropriate. However, if the aim is to consolidate existing research, identify gaps and assess the strength of evidence, then a textual narrative approach may be more useful. As the aim of the present review is to consolidate evidence regarding the demographic patterning of psychological beliefs about CRC screening, the narrative synthesis approach was deemed to be the appropriate method for synthesising data in this review.

#### **4.2.6 Data synthesis procedures**

Data from this review were synthesised using Popay et al., (2006)'s narrative synthesis approach as it allows the integration of qualitative and quantitative research and can be used to examine different relationships between the data.

There are four stages to the synthesis which are conducted in an iterative manner:

1. Developing a theory of how the intervention works, why and for whom
2. Developing a preliminary synthesis of the findings of included studies
3. Exploring relationships within and between studies
4. Assessing the robustness of the synthesis

The first step is not applicable to this review as it relates to the appraisal of intervention studies, the original purpose for which narrative synthesis was developed. However, narrative synthesis has recently been used more widely; for instance to understand lay views about hypertension adherence (Marshall, Wolfe et al. 2012) and attitudes towards organ donation among ethnic minority groups (Morgan, Kenten et al. 2012).

The purpose of the second stage is to develop an initial description of the included studies. The preliminary analysis was further interrogated to identify the factors influencing the results reported in the included studies. This was done with a view to developing an explanation of *why* particular psychological factors encompassing beliefs about CRC

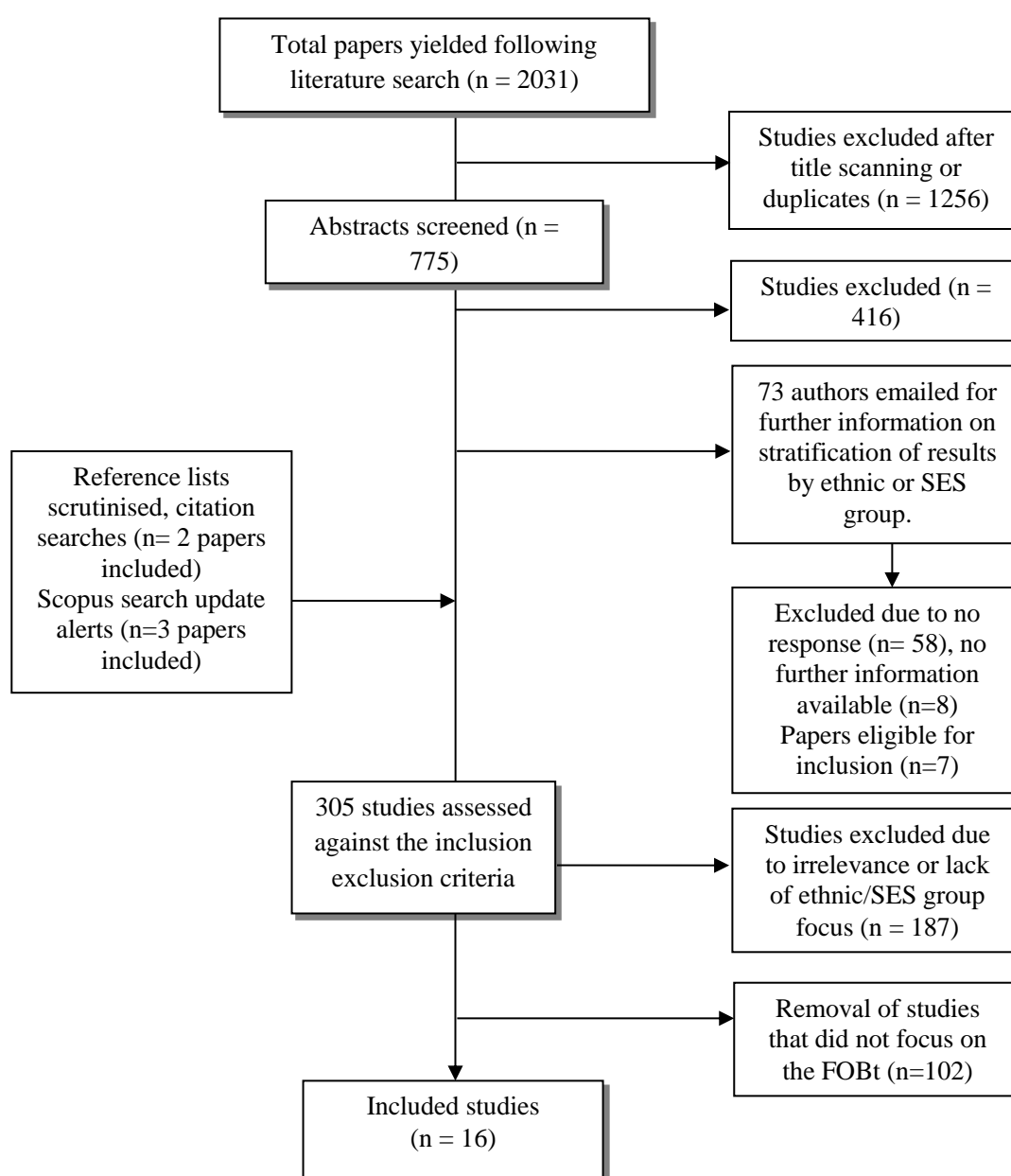
screening may differ by ethnicity and/or socio-economic factors. In order to explore, identify and describe patterns across and within studies, the data extracted from the included studies must be organised. This was done by tabulating the extracted data, grouping studies into clusters by: a) type (qualitative, quantitative or mixed methods) and b) participant demographic factors (ethnicity and/or SES). As both qualitative and quantitative evidence was considered, the results needed to be translated into a common rubric to allow meaningful comparisons to be made. In reviews consisting solely of numerical data, it is standard practice to transform results into a common statistical rubric, such as an effect size. This is not possible within a narrative synthesis review. However, some translation of findings into a common rubric is recommended by Popay et al., (2006). Thematic analysis is one option for translating data and can be applied to quantitative data by extracting the variable labels in survey research as 'themes'. Thematic analysis helps organise and summarise findings from large, diverse bodies of research. It is reported to work particularly well in reflecting the main ideas and conclusions across studies as opposed to developing new knowledge (Pope, Mays et al. 2007). However, as mentioned earlier, the approach has come under criticism for lacking transparency as it can be difficult to understand how and at what stage themes were identified (Lucas et al., 2007).

In this review, themes from included studies were organised according to the domains of the new validated version of the TDF (Cane et al., 2012). Beliefs across the domains were used as a basis for exploring relationships between the characteristics of participants, the contribution and, strength of relevant psychological factors. Sub-group analysis by study focus, ethnicity, SES, and both ethnicity and SES, was undertaken and qualitative descriptions of study findings were generated. A critical reflection about the robustness of this process completed the synthesis and is included in the discussion section of this chapter.

## 4.3 Results

### 4.3.1 Search results

The search identified a total of 2031 papers of which 118 papers were initially eligible for inclusion in the review. Following the removal of studies that did not focus on the FOBt, a total of sixteen studies were included. Figure 4.1, below, displays the study selection process.



**Figure 4.1:** Flow diagram displaying the study selection process

### **4.3.2 Characteristics of included papers**

#### **4.3.2i Focus of studies**

Findings of the narrative synthesis are organised according to the demographic focus of the studies included in this review. Six studies focused on SES indicators such as education, income and area deprivation. Six studies focused on ethnicity, of which three studies compared the views of different ethnic groups and three studies focused on single ethnic minority groups. Four studies focused on both ethnicity and SES.

#### **4.3.2ii Study designs**

Seven of the sixteen studies included in this review employed a qualitative design where data were mostly collected through focus groups (n=4 studies), as well as face-to-face interviews (n=2 studies) and telephone interviews (n=1 study). The remaining eight studies employed quantitative methods including cross-sectional (n=3), prospective (n=1), longitudinal (n=1), randomised controlled trials (n=2) or quasi-experimental (n=1) designs. One study employed mixed methods including both qualitative and quantitative elements. Almost all of the included studies were published in peer reviewed journals except two that were internal NHS or university reports, identified as grey literature.

#### **4.3.2iii Study settings and populations**

Six studies had been undertaken in the UK, six had been undertaken in the USA, three studies based in Australia and one study based in Spain.

Ethnic groups studied in the USA included African American, Asian, Latino/Hispanics, Chinese American and White American participants. British studies included participants from South Asian backgrounds as well as Vietnamese/Cantonese, African-Caribbean and



“Caucasian” participants. Furthermore, British studies tended to separate ethnic groups by regional origin and/or religion where people South Asian origin were studied in terms of Bengali, Gujarati, Punjabi Sikh, Muslim and Pakistani backgrounds. However, African and Caribbean groups were not separated and were instead studied as a combined unit. Similarly, studies from the USA also referred to participants of African or Caribbean origin generically as “African American” or “Blacks”. Contrary to UK studies that separated participants of Asian origin as South Asian or Vietnamese/Cantonese, studies based in the USA did not make this distinction between “Asian” participants. Australian studies included Italian Australian participants as well as White Australian participants and the only Spanish study included Spanish participants of varying SES backgrounds.

For SES, having low educational attainment, low income and residing in areas of high deprivation were considered to be indicators of lower SES. Conversely, those who were educated beyond high school, had higher household incomes and resided in areas of low deprivation were considered as higher SES by study authors. Additionally, American papers used health insurance coverage as a SES measure, whereby those with no insurance were considered to be of low SES.

Across all the studies, the majority of participants were within the age range of the UK CRC screening programme (60 to 69 years at the time of this review) although some of the large population based studies included younger age groups.

#### **4.3.2iv Psychological theory/constructs featured**

Only two of the sixteen studies included in this review named a specific theory when describing the theoretical framework for the study. The featured theories were the ‘Health Belief Model (HBM) and the Theory of Planned Behaviour (TPB). The majority of the remaining studies featured individual psychological constructs. Authors labelled these

constructs as “knowledge” (of CRC and screening), “awareness”, “understanding”, “attitudes”, “views”, “beliefs”, “barriers”, “facilitators”, “perceived susceptibility”, “risk perceptions”, “issues associated with participation”, “self-efficacy”, “fatalism”, “CRC worry”, “self-reported health”, “cancer fear”, and “intentions” or “willingness to take part in screening.”

#### **4.3.2v Quality of included studies**

The mean quality rating for papers that focused on SES was 61.50% (s.d 10.80), 58.10% (s.d 11.37) for papers that focused on ethnicity and 63.10% (S.D 8.13) for papers that focused on both ethnicity and SES. On the whole, quality scores tended to be higher for studies that focused on both ethnicity and SES and/or were qualitative, quasi-experimental, longitudinal, or randomised control trial (RCT) designs.

A notable criticism across quantitative papers was the lack of statistical assessment of reliability and validity of data collection measures. As it is unclear whether study measures were reliable, this casts an overall doubt on the reliability of the findings. A related criticism regarding data collection measures was the lack of explanation for the choice of data collection tool/questionnaire employed, such as references to reliability, and how suitable the measures were to fulfil the study objectives. Furthermore, the majority of quantitative papers did not explain their choice of sample size or demonstrate any evidence of a sample size calculation that would indicate if the study had adequate statistical power.

For qualitative papers, limitations in quality included the lack of consideration of sample size with regards to analysis and data saturation. Moreover, out of the seven qualitative studies included in this review, only three studies reported some assessment of the reliability of the analytic process, such as multiple authors being involved in analyses or triangulation of the findings.

Several criticisms were shared by both qualitative and quantitative studies. Firstly, despite all studies featuring psychological constructs as part of the data collection measures, the majority failed to make an explicit reference to a specific theoretical framework. Furthermore, as several authors employed generic terms such as “beliefs”, “barriers” and “views”, it was not always clear what the underlying psychological constructs being studied were. In a systematic review assessing the patterning of psychological beliefs in different demographic groups, the lack of an explicit theoretical framework in papers poses a challenge to the interpretation of the findings; this will be discussed further in the final section of this chapter. Another common weakness amongst quantitative and qualitative papers was the discussion of study strengths and limitations which may be important for the interpretation and generalisability of the findings. Although almost all papers discussed strengths, the discussion of limitations often lacked detail and for half the studies, was omitted entirely. The final limitation shared by both quantitative and qualitative studies concerned evidence of user involvement in study design. With the exception of two studies, (Szczepura, 2003 a & b, and Smith et al., 2010) none of the other studies in this review demonstrated any evidence of user involvement in study design or piloting of measures with members of the target study population prior to data collection. The latter point in particular may have relevance for studies that involved self-completion of questionnaires by participants with low levels of literacy. Piloting of questionnaires beforehand would have helped to ensure that questions were well defined, comprehensible and acceptable to members of the target population, thus increasing the validity of study measures and thereby, the findings.

### **4.3.3 Findings**

In the following section, the findings from the narrative synthesis are presented in three parts: first, papers that focused on SES, second, papers that focused on ethnicity and third,

papers that focused on both ethnicity and SES. Each section begins with a brief description of the results followed by a table summarising the studies to be discussed and finally, the narrative synthesis, organised by theoretical domains of the TDF.

#### **4.3.4i Papers focusing on SES (n=6 studies)**

Six studies examined psychological beliefs about CRC screening via the FOBt in relation to SES. Half of the studies were undertaken in the UK (McCaffery, Wardle et al. 2003, Miles, Rainbow et al. 2011, Frew, Wolstenholme et al. 2001), two studies were undertaken in Australia (Janda, Hughes et al. 2002) and (Smith, Trevena et al. 2010) and one study was undertaken in Spain (Molina-Barcelo, Salas Trejo et al. 2011). The latter Spanish study employed qualitative methods via focus groups whilst the majority of the remaining studies were quantitative, cross-sectional surveys (McCaffery et al., 2003, Frew et al., 2001 and Janda et al., 2002) alongside one randomised controlled trial (RCT) (Smith et al., 2010) and one longitudinal study (Miles et al., 2011). The main SES indicator was level of education, used as the sole indicator by three studies. One study used household income as the SES indicator (Frew et al., 2001) and the remaining two used a combined SES index. Miles et al., (2011) utilised an SES index comprising educational attainment, home and/or car ownership and Molina-Barcelo et al., (2011) utilised occupational social class and divided participants into two categories: low SES as ‘manual’ and high SES as ‘non-manual’.

In relation to study quality, studies ranged from 50% to 76% in quality scores. The longitudinal study by Miles et al., (2011) and the RCT by Smith et al., (2010) were amongst those with the highest quality scores. Table 4.1 overleaf, includes the main details of the studies that focused on SES, followed by the findings from the narrative synthesis. Table 4.2 at the end of this section displays the coverage of constructs from the Theoretical Domains Framework (TDF; Cane et al., 2012) by the individual studies. As can be seen in table 4.2, when psychological constructs explored by the studies were coded in terms of TDF domains,

the maximum number of TDF domains in any single study was four, where knowledge was the most commonly featured domain. Furthermore, one study featured three domains, two other studies featured two domains and two studies featured one domain each. Although the study by Smith et al., (2010) included several constructs, such as knowledge, attitudes and CRC worry, the data presented in the paper was not stratified by SES. The corresponding author did provide this information upon request but for one theoretical domain only: knowledge. Thus, this study was deemed as focusing on a single domain in relation to SES (Table 4.2).

**Table 4.1:** *Papers that focused on SES*

First author	Country	Design	Data collection method	Sample size	Participant characteristics as reported by authors	Psychological theory/ constructs studied as reported by authors	Study quality %
Frew et al., 2001	UK	Cross-sectional survey	Self-completed questionnaire	N=2769	<p>Age:  Under 45: 1080  45- 59: 928  60+: 748  Missing: 13</p> <p>Gender: men: 1025 women: 1744</p> <p>Ethnicity: “98% Caucasian”</p> <p>SES: Income:  0-£10,000: 770  £10-20,000: 964  £20-30,000: 567  &gt;£30,000: 468</p>	Perceived health status, CRC worry, perceived risk, importance of maintaining a healthy lifestyle, willingness to take part in screening and preference of screening test	50 %

<b>First author</b>	<b>Country</b>	<b>Design</b>	<b>Data collection method</b>	<b>Sample size</b>	<b>Participant characteristics as reported by authors</b>	<b>Psychological theory/ constructs studied as reported by authors</b>	<b>Study quality %</b>
Janda et al., 2002	Australia	Cross-sectional survey	Regional telephone survey including a brief, structured questionnaire using a computer-assisted telephone interviewing system	N=604	Mean age: 60 years  Gender: Men: 302, Women:302  SES: Education: No formal qualifications: 41 Primary school: 169 Junior high: 218 Trade/tech certificate: 116 University: 30	Perceived susceptibility to CRC, family history of CRC, knowledge about signs and symptoms of CRC, prior CRC screening behaviour, recommendations regarding CRC screening by the doctor, and likelihood of participation in future FOBt. Participants were also asked about barriers to, and facilitators of, FOBT, as well as beliefs related to early detection and treatment of CRC.	54.76%
McCaffrey et al., 2003	UK	Cross-sectional survey	Face-to-face questionnaire as part of the January 2000 Omnibus survey for the Office of National Statistics.	N= 1637	Age: 55 to74 Gender: Men: 763, Women: 874  SES: age left full time education: < 15 years: 165 15-18 years: 1098 19 years: 374	Knowledge, attitudes, and intention with regard to CRC – Theory of Planned Behaviour as a broad theoretical framework  Cancer experience	64.29%

<b>First author</b>	<b>Country</b>	<b>Design</b>	<b>Data collection method</b>	<b>Sample size</b>	<b>Participant characteristics as reported by authors</b>	<b>Psychological theory/ constructs studied as reported by authors</b>	<b>Study quality %</b>
Miles et al., 2011	UK	Longitudinal	Postal survey	N= 481	<p>Mean age 64 years</p> <p>Gender: Men:216 women: 265</p> <p>Ethnicity: 481 White, 48 non white</p> <p>Mean SES score= 2.19 where most participants had two of the three following SES indicators: high educational attainment, home or car ownership.</p>	<p>Self-rated health, depression</p> <p>Perceived threat-Susceptibility</p> <p>Cancer severity</p> <p>Cancer fear</p> <p>Response and self-efficacy</p> <p>Fatalism</p>	76.19%
Molina-Barcelo et al., 2011	Spain	Qualitative study	Focus groups	N=56	<p>Age: 50 to 69 years</p> <p>Gender: 32 women and 24 men</p> <p>SES: Social class</p> <p>“Manual” 32</p> <p>“Non-manual” 24</p>	<p>Level of knowledge about the disease and screening, perceived severity and susceptibility, the perceived benefits of participating in screening and the potential obstacles to and/or opportunities for participation. Opinion on screening invitation letter.</p>	52.38%



<b>First author</b>	<b>Country</b>	<b>Design</b>	<b>Data collection method</b>	<b>Sample size</b>	<b>Participant characteristics as reported by authors</b>	<b>Psychological theory/ constructs studied as reported by authors</b>	<b>Study quality %</b>
Smith et al., 2010	Australia	RCT	Self-completed questionnaire	N=586	SES: Education: No formal education: 14 Secondary school certificate: 392 Technical/trade: 180	Knowledge, attitude, informed choice, interest in screening, worry about developing CRC	71.43%

## **Narrative synthesis of papers that focused on SES**

### **Knowledge**

Studies examining knowledge consistently reported that those with higher levels of education (college and higher) had higher levels of knowledge about the signs and symptoms of CRC as well as awareness of screening (Janda et al., 2002 and Smith et al., 2010; Australia, McCaffery et al., 2003; UK). Participants across both studies with lower education (primary school or less), were found to be the least knowledgeable about CRC and screening.

### **Perceived consequences of CRC and screening**

In relation to perceived consequences of screening, participants with a tertiary level of education (university degree and above) were more likely to nominate ‘prevention’ as a motivator for screening and thought they were more likely to develop CRC, compared with participants with a lower level of education in a cross-sectional questionnaire survey in Australia (Janda et al., 2002). However, regardless of educational qualifications, participants on the whole agreed that treating CRC early increases a person’s chances of survival (Janda et al., 2002).

In contrast, in focus groups in Spain, Molina-Barcelo et al., (2011) did not identify any notable differences in the beliefs about consequences of CRC and risk perception by occupational social class. Participants of both high (“non-manual”) and low (“manual”) SES backgrounds regarded CRC as a serious illness and, on the whole, reported that they did not fully understand their risk of CRC and lacked reliable knowledge about risk factors. Thus, it appears that participants’ knowledge influenced their beliefs about the consequences of CRC and risk perceptions. This difference in findings between quantitative and qualitative studies reflects a limitation of comparing the results of both sets of studies. Statistically significant

findings in quantitative studies are heavily based on sample size which may appear to inflate differences between groups when they may be marginal. On the other hand, although analysis of qualitative studies can identify interesting patterns between different groups, they are limited in their ability to provide estimates of the strength of any relationships between different constructs, across different groups.

### **Optimism/pessimism**

Low SES groups were fatalistic about cancer compared to high SES groups, when SES was measured using educational qualifications, home ownership, and car ownership (Miles et al., 2011; UK).

### **Emotions**

Miles et al., (2011) found that people from lower SES backgrounds, who perceived their health to be poor, were more depressed than those who perceived their health to be good and were from the same SES category. However, as both depression and self-rated health were measured concurrently, the cross-sectional nature of the data makes it difficult to establish the causal relationship between SES, depression and self-rated health.

### **Beliefs about capabilities**

Self-efficacy for screening was found to be statistically significantly lower in people who were depressed and of low SES, than those who were not depressed or were of higher SES (Miles et al., 2011; UK).

### **Intentions**

The UK based questionnaire survey by McCaffery et al., (2003) found there was no difference in screening intentions by socio-demographics including educational attainment.

However, interest in screening was found to be related to level of household income by Frew et al., (2001). They found that people in receipt of a yearly household income below £10,000 were less likely to express an interest in screening than those who earned over £10,000 per year. Furthermore, people with higher incomes (>£30,000 per annum) were more likely to express a test preference, and this preference was more likely to be for the FOBt. However, the extent to which ‘interest’ in screening is theoretically similar to ‘intentions’ or plans to participate in screening, is questionable, making the comparability of the findings of both UK studies limited.

## **Goals**

Janda et al., (2002) found people educated to secondary level in Australia (completed high school), were more likely to report that they did not want to know if they had cancer or not, compared to those with lower (primary school only) or higher education (college or university). However, the authors did not speculate on the reasons for the educational difference in the findings.

## **Environmental context and resources**

A common obstacle to participating in FOBt screening for people of lower SES backgrounds, as measured by occupational social class, was the misunderstanding of the information contained in the invitation letter about the procedure for collecting and delivering samples e.g. thinking the medical practitioner would come to their homes to perform the test (Molina-Barcelo et al 2011; Spain).

## **Summary**

To summarise, the results presented in this section indicate there is some variation in knowledge, beliefs about consequences, optimism, emotions, goals, and intentions towards

screening via FOBt by SES. Five theoretical domains were not examined in the studies that focused on SES: 'behavioural regulation', 'memory, attention and decision', 'skills' and 'social role and identity'. Overall, people with higher educational attainment, college and above, had the greatest knowledge about CRC and screening compared to those who were educated to secondary level or less. Furthermore, participants of varying SES agreed early detection of CRC through screening would be a good idea. Low SES groups were found to be more fatalistic, depressed and perceived poorer health. Moreover, self-efficacy was lower in individuals who were depressed and from a low SES background. However, there were no statistically significant differences between socio-demographic factors including educational attainment in intentions to take part in screening (McCaffery et al., 2003). Another study from the UK found that those earning less than £10,000 per year had lower intentions towards screening via the FOBt (Frew et al., 2001). The finding that people educated to secondary level in Australia did not want to know if they had CRC or not, compared to those with more or less education was interesting (Janda et al., 2002). Closer examination of the groups however, revealed disparities in the sample sizes of the education level groups may have affected the findings as 427 participants were educated to primary level, 146 were educated to secondary level and only 30 were educated to college or beyond (Janda et al., 2002). However, how representative the latter group of participants were of people educated at college level in Australia remains unclear. Finally, people of low SES in Spain were more likely to report misunderstanding the procedure for FOBt completion, although beliefs about CRC and screening were not found to differ by SES (Molina-Barcelo et al., 2011).

**Table 4.2:** Coverage of the Theoretical Domains Framework by studies examining SES

<b>First author</b>	Knowledge	Beliefs about consequences	Beliefs about capabilities	Emotion	Intentions	Goals	Social influence	Optimism/pessimism	Environmental context/resources	Skills	Memory, attention, decision making	Social role and identity	Reinforcement	Behavioural regulation	<i>Number of domains per study</i>
Frew et al., 2001					✓										<i>1</i>
Janda et al., 2002	✓	✓				✓	✓								<i>4</i>
McCaffery et al., 2003	✓				✓										<i>2</i>
Miles et al., 2011			✓	✓				✓							<i>3</i>
Smith et al., 2010	✓														<i>1</i>
Molina-Barcelo et al., 2011		✓							✓						<i>2</i>
<b>Total coverage of each domain</b>	<i>3</i>	<i>2</i>	<i>1</i>	<i>1</i>	<i>2</i>	<i>1</i>	<i>1</i>	<i>1</i>	<i>1</i>	<i>0</i>	<i>0</i>	<i>0</i>	<i>0</i>	<i>0</i>	

#### **4.3.4ii Papers focusing on ethnicity (n=6 studies)**

Six studies focused on views about screening via FOBt in relation to ethnicity. Study details are presented in table 4.3. Three studies were based in the USA, two studies in the UK and one study was from Australia. Four studies were qualitative in design of which two studies collected data through semi-structured interviews (Choe, Tu et al. 2006, Severino, Wilson et al. 2009), one study conducted focus groups (Khan 2010) and one study conducted telephone interviews (Brouse, Basch et al. 2003). One study was a cross sectional questionnaire survey (Kim, Chapman et al. 2011) and the final mixed methods study was the report from the pilot trials of the CRC screening programme in the UK, described in two parts (Szczepura 2003a & b).

In terms of focus on ethnic groups, both USA based studies focused on Chinese American participants only and made no comparisons with any other ethnic groups (Choe, Tu et al. 2006, Kim, Chapman et al. 2011). Likewise, the study conducted in Australia by (Severino, Wilson et al., 2009) focused on Italian Australian participants only. One of the UK based studies (Khan 2010) exclusively focused on people of South Asian origin including Bengali, Indian and Pakistani participants. The other UK based study that was undertaken as part of the FOBt pilot screening evaluation included a more diverse and representative range of UK ethnic minority groups including African-Caribbean, Bengali, Punjabi Sikh, Gujarati, Pakistani and Vietnamese/Cantonese participants (Szczepura 2003a & b).

Study quality scores varied vastly, ranging from 45.24% to 69.05%, with the median being 61.90%. The highest quality score was for a qualitative interview study (Choe et al., 2006) and the lowest was another qualitative study (Brouse et al., 2003). Coverage of the TDF ranged from one to nine domains, with the maximum domains covered in the combined focus group and questionnaire methodology that was employed in the UK CRC screening pilot report. Knowledge, Beliefs about Consequences and Emotions were the most

commonly featured domains as displayed in table 4.4. Findings from the narrative synthesis follow table 4.3, overleaf.



**Table 4.3: Papers that focused on Ethnicity**

<b>First author</b>	<b>Country</b>	<b>Design</b>	<b>Data collection method</b>	<b>Sample size</b>	<b>Participant characteristics, as reported by authors</b>	<b>Psychological construct/theory studied, as reported by authors</b>	<b>Study quality %</b>
Brouse et al., 2003	USA	Qualitative	Telephone interviews	N=8	Aged 54 to 72 years.  Gender: 2 men and 6 women  Ethnicity: 5 Hispanic, 2 “Black” and 1 “White”	CRC knowledge, stage of readiness to change, preference of screening test, access to resources, skills and social support	45.24%
Choe et al., 2006	USA	Qualitative study	Face-to-face semi-structured interviews	N=30	Chinese American women aged 50 to 79 years  Median years of education: 10 years  63% reported poor or no English	General health and cancer beliefs, prevention and beliefs about CRC as well as understanding and experience of FOBt.	69.05%
Khan, 2010 (NHS Oldham)	UK	Qualitative study	Focus groups	N=99 participants across 11 focus groups	Ethnicity: 44 Pakistani, 35 Bangladeshi and 17 Indian	Views about CRC screening	47.62%
Kim et al., 2011	USA	Prospective survey	Self-completed questionnaire	N=113	100% Chinese American sample Mean age 61 years.  Gender: Men: 40, Women: 73	CRC risk perceptions	45.24%

First author	Country	Design	Data collection method	Sample size	Participant characteristics, as reported by authors	Psychological construct/theory studied, as reported by authors	Study quality %
Severino et al., 2009	Australia	Qualitative	Face-to-face semi-structured interviews	N=20	Italian Australian participants aged 54-74 years  Gender: Men: 7, Women: 13  “The majority had completed primary education.”	Exploration of the variables included in the Health Belief Model. Topic guide discussed included knowledge of cancer, CRC and FOBt; values underlying health behaviour; and perceived benefits and barriers of screening with FOBt.	69.05%
Szczepura et al., 2003a	UK	Mixed methods: Questionnaire and Qualitative study	Focus groups	N= 150	Ethnicity: 27 African Caribbean, 44 Bengali, 25 Punjabi Sikh, 10 Vietnamese/Cantonese, 31 Gujarati, 13 Pakistani	Knowledge of, and attitudes towards, CRC and cancer in general. Attitudes towards screening Issues associated with participation in the FOBt screening process and suggestions as to how to increase uptake	59.52%

<b>First author</b>	<b>Country</b>	<b>Design</b>	<b>Data collection method</b>	<b>Sample size</b>	<b>Participant characteristics, as reported by authors</b>	<b>Psychological construct/theory studied, as reported by authors</b>	<b>Study quality %</b>
Szczepura et al., 2003b	UK	Mixed methods: Questionnaire and Qualitative study	Postal questionnaire	N=783	Aged 50 to 69 years  Gender: 396 men and 387 women  Ethnicity: 87 Hindu-other, 194 Hindu-Gujarati, 191 Muslim 311 Punjabi-Sikh.	Understanding beliefs and attitudes concerning response to FOBt versus non-response Evaluating psychological distress following FOBt invitation	54.76%

## **Narrative synthesis of papers that focused on ethnicity**

### **Knowledge**

Lack of knowledge of CRC and screening was reported as an obstacle to screening in some of the studies that examined beliefs about the FOBt (Brouse et al., 2003; USA, African American, Hispanic and White American participants, Khan, 2010; UK, Bengali, Indian and Pakistani participants, Szczepura, 2003a; UK, African Caribbean, Bengali, Punjabi Sikh, Vietnamese/Cantonese, Gujarati and Pakistani participants). In a UK based study involving South Asian participants, Khan, (2010) found a lack of awareness of CRC was common alongside very little understanding of symptoms and causes of CRC. This led to some participants ignoring screening invitation letters as they did not understand what they related to. However, focus groups undertaken with African Caribbean, Bengali, Punjabi Sikh, Vietnamese/Cantonese, Gujarati and Pakistani people during the pilot of the CRC screening programme found that nearly every community had some awareness of CRC (Szczepura, 2003a). For men, knowledge of their wives' opportunities for, and previous experiences of cancer screening influenced attitudes towards screening (Szczepura, 2003a). Despite being aware of CRC, knowledge of the disease or its implications was reported to be virtually non-existent. Furthermore, many members of minority ethnic groups stated they would not respond to a postal FOBt invitation unless they had prior warning or awareness of screening and advocated the need for community and tailored language promotion of screening (Szczepura, 2003a). After receiving more information about the nature of the screening programme, the same participants were inclined to respond more positively, following their initial reluctance (Szczepura, 2003a).

In the US, the lack of past experience of the FOBt and confusion over the purpose of the test were cited as knowledge based obstacles to participation in screening for Chinese American participants in a qualitative study (Choe et al., 2006). In contrast, other participants in the

same study who believed that regular stool examinations were important were more willing to participate in screening via the FOBt (Choe et al., 2006). There were also some interesting culturally specific aspects that underpinned Chinese American participants' knowledge of CRC. Based on some traditional Chinese beliefs that categorise foods, medications and illnesses as having "hot" or "cold" effects on the body, participants equated certain foods with higher risk of CRC due to intrinsic "heat" or toxins present within them (Choe et al., 2006). Furthermore, constipation was viewed as central to the formation and retention of toxins in the body. As noted by the authors, these beliefs about the causes of CRC are not consistent with the clinical explanation of CRC where constipation and change in bowel habit may represent symptoms of the disease rather than being precursors.

### **Beliefs about consequences**

Consideration of the consequences of screening via FOBt included discussion of the potential benefits. For instance, participants from all ethnic groups believed completion of the FOBt would detect any abnormality, lead to earlier and less drastic treatment as well as reduce worry about cancer (Szczepura, 2003a). In another prospective study including Chinese American participants, Kim et al., (2011) found that regardless of how at risk of CRC participants felt, the majority believed CRC could be prevented and cured (Kim et al., 2011).

Another important consideration of consequences by UK ethnic groups included the need for some form of treatment to be available should participants be diagnosed with CRC as well as the belief that early detection would increase the chance of successful treatment (Szczepura, 2003a; UK, African Caribbean, Bengali, Punjabi Sikh, Gujarati, Pakistani, and Vietnamese and Cantonese participants). In contrast, Italian Australians believed that despite being treated, a person would not be completely cured of cancer as the 'root' of the cancer may have grown and spread to other parts of the body (Severino et al., 2009). These differences

in the views of UK and Australian ethnic minority groups may reflect cultural differences in the way in which cancer is conceptualised and perceived.

### **Optimism/Pessimism**

Fatalistic beliefs about cancer in general were held by some South Asian participants who believed a cancer patient was in God's hands and that death from cancer was inevitable (Szczepura, 2003 a&b). However, other participants within the same cohort challenged these views and did not believe that fate was inexorable or that it should not be changed by actions such as screening (Szczepura, 2003 a&b). Furthermore, participants on the whole believed it was better to know if they had CRC rather than to live in ignorance; although being aware of how screening would be personally beneficial to them would also encourage their participation (Szczepura, 2003 a&b). Thus, people's beliefs about fate and their goals, such as wanting to know if one had CRC or not, were formed on the basis of their understanding of screening and its benefits.

Italian Australian participants believed cancer in general was present inside every person's body although it does not go on to develop in everyone (Severino et al., 2009). Furthermore, CRC was perceived as being a serious disease due to its hidden nature as well as a lack of control over who develops it, which also contributed to Italian Australian participants' fatalistic views about cancer survival (Severino et al., 2009). Once again, this suggests that cultural understanding and conceptualisation of cancer may give rise to fatalistic beliefs about survival.

### **Emotions**

South Asian participants in the UK were more likely to be concerned that the FOBt would be disgusting, embarrassing or unhygienic to complete than White European participants

from earlier FOBt screening pilots (Szczepura, 2003b). Moreover, there were no significant differences in perceptions of disgust and embarrassment between “Hindu other”, “Hindu Gujarati”, “Muslim” and “Sikh Punjabi” participants in the UK (Szczepura 2003b). In US studies, fear of cancer being detected was a worry for some African American, Hispanic, Chinese American (Brouse et al., 2003, Choe et al., 2006). This was also true for Italian Australian participants (Severino et al., 2009). Chinese Americans also cited reluctance and embarrassment to discuss screening through interpreters (Choe et al., 2006). As well as negative emotions towards screening, Italian Australian participants believed negative feelings such as stress, sorrow, anxiety and anger contributed to causing cancer (Severino et al., 2009).

### **Beliefs about capabilities**

High self-efficacy, measured in terms of confidence of being able to complete the FOBt, encouraged people to take part in screening via FOBt, regardless of their ethnicity (Szczepura 2003a, Brouse et al., 2003). The majority of South Asian participants in the UK screening pilots perceived the FOBt to be easy to complete and were confident in their ability to complete it (Szczepura 2003b). However, Muslim participants were the least confident about their ability to complete the FOBt although no specific reason was identified for their lower self-efficacy (Szczepura 2003b). In addition, people’s perception about the efficacy of screening was often based on how much confidence they had in their doctor and local hospitals (Szczepura 2003a; African Caribbean, Bengali, Punjabi Sikh, Gujarati, Pakistani, and Vietnamese and Cantonese participants).

Chinese American participants raised concerns regarding difficulties adhering to dietary restrictions which are a requirement of certain variant types of the FOBt (Choe et al., 2006). This finding may be irrelevant to the UK as dietary restrictions are not required for FOBts that are currently used in the UK CRC screening programme.

## **Skills**

Difficulties reading and understanding English were reported as obstacles to screening for Chinese American participants (Choe et al., 2006), South Asian participants in the UK (Szczepura, 2003a) and Hispanic participants (Brouse et al., 2003). Furthermore, Chinese American participants were reluctant to ask questions when explanations given by their doctor were not understood. In contrast, only two out of 20 Italian Australian participants reported the inability to speak/read English as a barrier to FOBt completion in a qualitative study (Severino et al., 2009). One possible reason for this finding may be that as participants were asked about the specific barriers to completing the FOBt, they tended to focus on more procedural issues rather than the more generally applicable barrier of language.

## **Social Influence**

Lack of social support and encouragement from family and community leaders was reported discourage screening for Hispanic participants in the USA (Brouse et al., 2003) as well as South Asian participants in the UK CRC screening programme (Szczepura, 2003b). Hindu-Gujarati participants in the UK reported the lowest levels of social support for participating in CRC screening, whereas Punjabi Sikh participants reported the highest levels of social support (Szczepura, 2003b). In another focus group study with South Asian participants in Oldham, UK, some participants reported that the lack of promotion of screening by healthcare staff led them to believe it was not important (Khan, 2010).

As reported in the previous section, recommendation of, and prior education about screening by one's family doctor was a strong facilitating factor for people to take part in screening (Choe et al., 2006; Chinese American participants), and was even more helpful if the doctor spoke the same language as the participant (Severino et al., 2009; Italian Australian participants). Moreover, family recommendation was also found to further encourage ethnic



minority participants to take part in screening via FOBt (Severino et al., 2009). For South Asian participants, low levels of literacy meant adults relied on their family (usually children) to advise about postal material, with some people reporting that their children controlled or protected them from “intrusive surveys” and other unwanted post (Szczepura, 2003a; UK).

## **Goals**

A minority of South Asian participants in the UK reported that their health was not a concern, having not experienced any health related issues and, as such, participating in CRC screening was not of interest to them (Szczepura, 2003a). Thus, lack of symptoms and good general perceived health determined the priority of behaviours such as CRC screening. However, participants with a more sophisticated understanding of screening realised it was not a ‘once only’ event, but formed part of a longer-term health maintenance plan with the potential to avert future problems (Szczepura, 2003 a&b).

## **Environmental context and resources**

Worry about the monetary cost of using a FOBt was a concern for Chinese Americans in a USA based interview study (Choe et al., 2006). Closer examination of the data revealed that participants who were the most concerned about the cost of screening also did not have any health insurance (Choe et al., 2006). Furthermore, work environment restrictions were reported to conflict with completion of the FOBt (Choe et al., 2006). The unavailability and inaccessibility of FOBts was also a barrier for a small sample of Hispanic (n=5), African American (n=2) and White American (n=1) participants in the USA (Brouse et al., 2003).

The experience of gastrointestinal related symptoms prompted people to take part in screening (Choe et al., 2006; Chinese American participants). Similarly, those who did not

experience symptoms or did not believe in asymptomatic screening were less inclined to take part in screening (Choe et al., 2006).

UK participants from a range of ethnic minority backgrounds including African-Caribbean, Bengali, Punjabi Sikh, Gujarati, Pakistani, and Vietnamese and Cantonese backgrounds perceived being able to complete the FOBt at home as convenient (Szczepura, 2003a).

### **Social role and identity**

Resistance to screening via FOBt was rarely reported due to religious or cultural grounds in the UK (Szczepura, 2003a; African Caribbean, Bengali, Punjabi Sikh, Gujarati, Pakistani, and Vietnamese and Cantonese participants). Additionally, some South Asian participants viewed taking part in mass screening as a communal activity and perceived it to be part of their duty to the community, reflecting a collectivist stance, associated with populations where behaviour and goals are orientated towards the community (Szczepura, 2003a).

### **Summary**

In summary, studies that examined beliefs about CRC screening by ethnicity tended to be qualitative in design and were of modest quality. The majority of qualitative studies did not comment on the reliability of the analytic process so the findings should be interpreted with caution. Although most studies did not specify an explicit theoretical framework, there was good coverage of the TDF domains, except for four domains that were not covered. These were ‘intention’, ‘behavioural regulation’, ‘memory, attention and decision’, and ‘reinforcement’.

In terms of findings, many similarities were evident in the views of different ethnic minority groups across the various TDF domains such as, the perceived benefits of screening in the

‘Beliefs about Consequences’ domain. However, there were some mixed findings. Regarding ‘Knowledge’, the majority of studies found that the lack of knowledge about screening was a reported obstacle for USA and UK ethnic minority groups (Brouse et al., 2003, Khan, 2010, Szczepura, 2003a). In contrast, in focus groups with UK ethnic minority groups, it was apparent that nearly every community had some awareness of CRC (Szczepura, 2003a). Nevertheless, UK ethnic minority groups reported they would not participate in screening unless they had prior awareness about it (Szczepura, 2003a).

With regards to ‘Emotions’, there were no significant differences in perceptions of disgust and embarrassment of the FOBt between South Asian “Hindu other”, “Hindu Gujarati”, “Muslim” and “Sikh Punjabi” participants (Szczepura, 2003b). In terms of ‘Beliefs about Capabilities’, the majority of South Asian participants in the UK perceived the FOBt to be easy to complete and were confident in their ability to do so (Szczepura, 2003b). However, Muslim participants were the least confident about their ability to complete the FOBt, although there was no clear reason given for their lower self-efficacy (Szczepura, 2003b).

When considering ‘Social Influence’, the lack of recommendation for screening from doctors, as well as low perceived social support and encouragement from family and community discouraged minority groups in the USA and UK to participate in screening. Focus groups undertaken with African Caribbean, Bengali, Punjabi Sikh, Vietnamese/Cantonese, Gujarati and Pakistani people during the pilot of the CRC screening programme in the UK found many people would not respond to a postal FOBt invitation unless they had prior warning or awareness of screening (Szczepura et al., 2003a). They also advocated the need for greater community and tailored language promotion of screening (Szczepura et al., 2003a). However, some differences within South Asian groups in the UK were evident whereby “Hindu-Gujarati” participants reported the lowest levels of social support, whereas “Punjabi Sikh” participants reported the highest levels of social support.

Perceived social support was associated with how important people perceived screening to be.

In relation to the 'Social role and identity domain', UK ethnic minority groups were not deterred from screening by religious or cultural grounds (Szczepura, 2003 a&b). Fatalistic beliefs about cancer in general in the 'Optimism/pessimism' domain were found to be held by some South Asian participants who believed a cancer patient was in God's hands and that death from cancer was inevitable (Szczepura, 2003a). However, other participants within the same cohort challenged these views and did not believe that fate was inexorable or that it should not be changed by actions such as screening (Szczepura, 2003a). Fatalistic beliefs were also evidenced by some Italian Australian participants (Severino et al., 2009). In terms of 'Skills', difficulties reading and understanding English were obstacles to screening via FOBt for a range of ethnic minority groups in the UK, USA and Australia (Choe et al., 2006; Chinese American participants, Szczepura, 2003b; South Asian participants and Severino et al., 2009; Italian Australian participants).

For 'Environmental, context and resources', minority groups in the USA reported concerns about the monetary cost of the FOBt (Choe et al., 2006) and difficulties obtaining the test kits (Brouse et al., 2003). Furthermore, lack of gastrointestinal symptoms made Chinese American participants less inclined to undergo screening (Choe et al., 2006) but this was not mentioned as a concern by UK ethnic minority groups.

**Table 4.4:** Coverage of the Theoretical Domains Framework by studies examining ethnicity

First author	Knowledge	Beliefs about consequences	Beliefs about capabilities	Emotion	Intentions	Goals	Social influences	Optimism/pessimism	Environmental context/resources	Skills	Memory, attention, decision making	Social role and identity	Reinforcement	Behavioural regulation	Total domains covered
Brouse et al., 2003	✓		✓	✓			✓		✓	✓					6
Choe et al., 2006	✓		✓	✓			✓		✓	✓					6
Khan, 2010	✓						✓								2
Kim et al., 2011		✓													1
Severino et al., 2009		✓		✓			✓	✓		✓					5
Szcepora et al., 2003	✓	✓	✓	✓		✓	✓	✓		✓		✓			9
<i>Total coverage of each domain</i>	<i>4</i>	<i>3</i>	<i>3</i>	<i>4</i>	<i>0</i>	<i>1</i>	<i>4</i>	<i>2</i>	<i>2</i>	<i>4</i>	<i>0</i>	<i>1</i>	<i>0</i>	<i>0</i>	

#### **4.3.4iii Papers focusing on ethnicity and SES (n=4 studies)**

Four studies examined perceptions of CRC screening by FOBt, in relation to both ethnicity and SES. Table 4.5, on the following page, includes the main details of the studies presented in this final section of the results. Three of the four studies were based in the USA (O'Malley, Beaton et al. 2004, Schroy, Glick et al. 2008 and Weinrich, Weinrich et al. 1992), and the remaining study was based in the UK (Techer, Weller et al., 2009). Two studies employed a qualitative design (O'Malley, Beaton et al. 2004, (Techer, Weller et al., 2009) one study was part of a RCT (Schroy, Glick et al. 2008) and one study employed quasi-experimental methods (Weinrich, Weinrich et al. 1992). Study quality scores ranged between 52.38% and 71.23%, where a USA based quasi-experimental study had the highest score (Weinrich, Weinrich et al. 1992).

In relation to coverage of the TDF, focus groups undertaken by Techer et al., (2009) in the UK uncovered themes relating to knowledge, beliefs about consequences, beliefs about capabilities, emotion, social influences, optimism/pessimism, environmental context and resources, social role and identity and behavioural regulation (see table 4.6). The latter study also had the most coverage of TDF domains (n=9) in papers that focused on both ethnicity and SES. Three domains including, goals, memory, attention and decision making, and reinforcement were not covered by any of the studies that focused on ethnicity and SES. A note to bear in mind about Techer et al., (2009)'s study is the comparison between South Asian participants and Scottish participants who lived in areas of high deprivation. The ethnicity of the Scottish participants and the socio-economic situation of the South Asian participants were not reported, so although the report presents comparisons between groups it does not provide evidence regarding whether any apparent patterning of beliefs attributed to ethnicity may also be a function of participants' SES.

**Table 4.5:** *Papers that examined ethnicity and SES*

First author	Country	Design	Data collection method	Sample size	Participant characteristics, as reported by authors	Psychological theory/ constructs studied, as reported by authors	Study quality %
O'Malley et al., 2004	USA	Qualitative	Focus group	N=40	<p>Aged 50 to 75 years. Gender: Men: 22, Women: 18</p> <p>Ethnicity: African American: 34, Other: 6</p> <p>SES: Education Up to high school: 29 Post high school: 11 None of the participants had any health insurance</p>	<p>Feelings about and experiences with colorectal cancer screening</p> <p>CRC awareness</p> <p>Attitudes</p> <p>Barriers to screening</p> <p>Barriers to health care access</p> <p>Facilitators of screening</p>	61.90%
Schroy et al., 2008	USA	RCT designed to assess the impact of a decision aid on shared decision-making and CRC screening behaviour.	Self-completed questionnaire as part of the RCT	N=356	<p>The majority were aged under 65 years Gender: Women: 206, Men: 150</p> <p>Ethnicity: White: 130, Black: 213 Asian: 6 Other: 6</p> <p>SES: Education: &gt; high school : 213 High school or less: 143</p>	Knowledge, beliefs, attitudes and behaviours related to CRC screening.	52.38%

First author	Country	Design	Data collection method	Sample size	Participant characteristics, as reported by authors	Psychological theory/ constructs studied, as reported by authors	Study quality %
Techer et al., 2009	UK	Qualitative study	Focus groups	N=16 focus groups in total: 8 in Scotland and 8 in the West Midlands.  Overall sample size was not specified.	Ethnicity: Hindu Gujarati, Sikh Punjabi, Muslim Bengali, Muslim Urdu participants from the West Midlands.  SES: participants from high deprivation areas in Scotland	Barriers and facilitators of CRC screening	66.67%
Weinrich et al., 1992	USA	Quasi-experimental pre test-post-test 2x2 factorial design for a CRC educational intervention	Face- to-face questionnaire at baseline	N=211	Mean age 72 years (SD 11)  Gender: Women: 145, Men: 43  Ethnicity: 108 African American 103 Caucasian  SES: Mean level of education was 8th grade (SD 3.8). Income: 50% less than the poverty level of \$6,268 per year	CRC knowledge	71.43%



## **Narrative synthesis of papers that focused on ethnicity & SES**

### **Knowledge**

Lack of awareness of CRC was reported as a barrier to screening by both South Asian participants of unknown SES and low SES Scottish participants (of unknown ethnicity) in focus groups undertaken as part of the evaluation of the UK screening programme (Techer et al., 2009). USA based studies found differences in knowledge by both ethnicity and SES. Knowledge of CRC, symptoms and screening was statistically significantly higher in “White” American participants than “Black” participants (Schroy et al., 2008, Weinrich et al., 1992). Furthermore, participants with high school or higher level of education (Schroy et al., 2008) and those who earned over \$10,000 per year (Weinrich et al., 1992) were also more knowledgeable compared to those who were less educated and had a low income. In a qualitative study in the USA, African American participants, who had low incomes and all lacked health insurance, reported low levels of knowledge about screening and especially about the procedure for FOBt as barriers to screening (O’Malley et al., 2004). Although some participants perceived the FOBt as distasteful, the majority reported they would still do the test if they had more knowledge about its benefits and the procedure (O’Malley et al., 2004).

### **Perceived consequences of CRC**

South Asian participants of unknown SES and low SES Scottish participants (of unknown ethnicity) reported similar perceived benefits of CRC screening in focus groups conducted by Techer et al., (2009). Participants believed taking part in screening would give them peace of mind, reduce worry and that prevention was better than cure. This latter benefit of screening alongside the lack of pain and safety of the test were also mentioned by low SES African American and “other” minority group participants in the USA, (O’Malley et al.,

2004). In the UK, some low SES Scottish participants were concerned about the length of time needed to wait to receive FOBt results which may cause additional distress (Techer et al., 2009). Moreover, they also reported concerns about the potential contamination of the faecal samples as well as concerns about the adequacy of the cardboard sticks used to collect samples that were not mentioned by the South Asian group.

### **Optimism**

Overly high or unrealistic optimism about one's risk of CRC was a common discouraging factor for screening participation for both UK South Asian participants of unknown SES as well as Scottish participants who lived in areas of high deprivation (of unknown ethnicity) (Techer et al., 2009). In addition, some South Asian participants of Bengali and Punjabi origin held fatalistic beliefs regarding the onset of illness being "written" by God (Techer et al., 2009). However, these fatalistic beliefs did not appear to reduce participants' sense of responsibility for their health, as discussed later in the 'social role and identity' domain.

### **Emotions**

Embarrassment and disgust were commonly reported as obstacles to screening via FOBt by both South Asian participants of unknown SES and low SES Scottish participants (of unknown ethnicity) (Techer et al., 2009). In addition, the emotions of worry, fear and shock were elicited as connotations of the word 'cancer' for South Asian participants although this was not mentioned by the Scottish participants (Techer et al., 2009).

### **Social influence**

The importance of general practitioner (GP) contact and follow up were deemed as important to encourage people's initial and subsequent engagement in screening by both South Asian participants and Scottish participants who lived in areas of high deprivation (of

unknown ethnicity) (Techer et al., 2009). Moreover, discussion with family and friends, particularly partners, positively influenced South Asian and Scottish participants towards screening (Techer et al., 2009). Additionally, having someone explain the screening process and purpose of screening also encouraged people to take part (Techer et al., 2009). Furthermore, low SES African American participants in the USA also wanted regular reminders for screening from their doctor to help prioritise completion of the FOBt (O'Malley et al., 2004).

### **Beliefs about capabilities**

Many South Asian participants reported language barriers would hinder their ability to understand information regarding screening and that they would seek advice from community sources as well as their friends and family; this was not mentioned by low SES Scottish participants (of unknown ethnicity) (Techer et al., 2009).

### **Environmental context and resources**

Lack of bowel related symptoms was a barrier to screening for both South Asian participants (of unknown SES) and Scottish participants (of unknown ethnicity) (Techer et al., 2009). Similarly, not believing in screening without symptoms was also reported to hinder future participation in screening for both groups, as well as for low SES African American participants in the USA (O'Malley et al., 2004).

The lack of health insurance coverage was reported as a barrier to screening by low SES African American participants in the USA, all of whom lacked such insurance (O'Malley et al., 2004). Furthermore, the majority of participants in this qualitative study reported there was no point being screened if one could not pay for any subsequent treatment required. Moreover, screening was deemed as low priority in relation to participants' other, more

acute health concerns in this sample of low SES African American individuals. However, a significant promoter of screening for these participants was the geographic proximity and evening/weekend accessibility of colonoscopy facilities, should they be required (O'Malley et al., 2004).

Through multiple focus groups, Techer et al., 2009 found that the privacy of completing the FOBt at home was perceived as a benefit of screening by both South Asian participants (of unknown SES) and low SES Scottish participants (of unknown ethnicity).

### **Behavioural regulation**

Low SES Scottish participants discussed the need to get themselves organised to complete the FOBt and be clear on the instructions prior to attempting completion. These issues were not mentioned by South Asian participants (of unknown SES) (Techer et al., 2009). African American participants in the USA reported that clearer instructions on how to complete the FOBt including collection of the sample, amount of sample required and food restrictions would increase the likelihood of them completing it in the future (O'Malley et al., 2004).

### **Social role and Identity**

Taking part in screening was perceived to be a religious duty by South Asian participants (of unknown SES) as it was part of taking care of one's general health (Techer et al., 2009). Low SES Scottish participants discussed gender differences in the acceptability of screening with lower acceptability perceived in men who did not view screening as a male activity (Techer et al., 2009).

## Summary

In summary, although only four studies focused on screening via FOBt, rich data was available, mainly due to the two qualitative studies undertaken by O'Malley et al., (2004) and Techer et al., (2009). Despite the richness of the data, there was no evidence on five domains ('intentions', 'goals', 'skills', 'memory, attention and decision', and 'reinforcement') in relation to ethnicity and SES factors. Overall, Scottish participants of low SES and South Asian participants of unknown SES, residing in the West Midlands, held very similar views about CRC screening. For instance, awareness of screening was similar across both groups as were perceptions of the benefits of screening, social influences, perceptions of disgust and embarrassment as well as unrealistic optimism over one's risk of developing CRC. There were some slight differences; low SES Scottish participants reported greater concerns over contamination of the sample, time needed to wait for the results and the agility of the cardboard sticks that accompany the FOBt kit. South Asian participants, on the other hand, reported language barriers would be an obstacle to participating in screening as they needed help reading and understanding instructions for test completion. In addition, some South Asian participants also held fatalistic beliefs about getting cancer but still viewed undertaking screening as part of their wider religious duty, an aspect not discussed by Scottish participants. In relation to USA based studies, high income and education as well as 'White' ethnicity were associated with higher levels of CRC screening knowledge (Schroy et al., 2008 and Weinrich et al., 1992). For low income African American participants, low knowledge about screening, procedural issues relating to the FOBt and lack of insurance coverage were all barriers to screening (O'Malley et al., 2004). A final note regarding study quality scores; the studies reviewed in this section were only marginally higher in quality than studies in previous sections, weak areas related to the lack of an explicit theoretical framework, sample size consideration (where appropriate) and lack of user involvement.

**Table 4.6:** Coverage of the Theoretical Domains Framework by studies examining Ethnicity and SES

First author	Knowledge	Beliefs about consequences	Beliefs about capabilities	Emotion	Intentions	Goals	Social influence	Optimism/pessimism	Environmental contexts	Skills	Memory, attention, decision	Social role and identity	Reinforcement	Behavioural regulation	Number of domains per study
O'Malley et al., 2004	✓	✓					✓		✓					✓	5
Schroy et al., 2008	✓														1
Techer et al., 2009	✓	✓	✓	✓			✓	✓	✓			✓		✓	9
Weinrich et al., 1992	✓														1
Total coverage of each domain	4	2	1	1	0	0	2	1	2	0	0	1	0	2	

#### **4.4i Discussion of findings**

This review aimed to examine the linkages between ethnicity, SES and psychological constructs in relation to CRC screening.

On the whole, there were far more similarities than differences between the views of different ethnic groups with all groups tending to agree CRC was a serious disease and that early detection could increase chances of survival. The authors of the UK CRC screening pilot studies commented that there were fewer differences in the views of the different South Asian ethnic groups than between groups of well educated or less educated participants (Szczepura, 2003a). Nevertheless, there were some areas of difference between different ethnic groups such as the experience of language barriers for non-English speaking ethnic groups as reported by South Asian participants in the UK and Hispanic participants in the USA. Low SES groups and some ethnic minorities (South Asian participants in the UK and Italian participants in Australia) were more fatalistic about cancer although recommendation of screening by doctors was a strong facilitator for these groups.

In relation to SES, the context in which screening is offered also warrants attention as this affects the generalisability of the findings of this review. In the USA, screening is not delivered as part of an organised population screening programme as is the case in the UK and Australia. Moreover, the monetary cost of screening that was a barrier to screening in some American studies, and was strongly related to SES, is also irrelevant to UK practice as screening is offered free at point of use.

Attention must be given to the definitions and measurement of SES and ethnicity in the studies included in this review. In relation to SES, the most commonly included indicators were educational attainment, income and neighbourhood deprivation. As outlined in chapter 2, educational attainment is a fairly good measure of SES due its independent relation to

health, however many studies in this review tended only to focus on years completed which provides little information about actual attainment. Reliance on income as an SES measure alone however, is a potentially flawed indicator for people who are of retirement age and not economically active (Grundy and Holt 2001). Area deprivation is also not an ideal measure of SES as it views residents within particular areas as homogenous, thus disregarding any variation in individuals'/family's socio-economic circumstances (Morris, Baio et al. 2012). As very few studies used multiple SES indicators, comparisons between studies were often made across differing SES indicators, resulting in conflicting results in some instances. One example is the finding that intentions did not vary by education, measured as the age at which participants left full-time education (McCaffery et al., 2003), but did vary by income where those with low income had lower intentions compared to those with higher incomes (Frew et al., 2001). This discrepancy in findings of studies using different measures of SES may reflect the bias in using 'years completed' as an indicator for education as it does not always guarantee that any learning/attainment took place, as discussed in chapter two. Apart from the type of SES measure, another reason for the inconsistent findings in the latter example could be due to the quality of the studies themselves. Although the study by Frew et al., (2001) had just over 1000 participants more than the study by McCaffery et al., (2003), the quality of the latter study was better in terms of having an explicit theoretical basis, thereby yielding potentially better measures. A further alternative explanation may be that income and education may influence screening intentions in different ways or through differential mechanisms, some of which will be explored in chapter six of this thesis.

In relation to ethnicity, the findings of studies undertaken in the USA with African American, Hispanic and Chinese American participants suggested there were a number of factors that appeared to deter ethnic minority groups from screening. Many of these potential obstacles to screening, such as low knowledge, embarrassment and perceived lack of social support were shared by UK ethnic minority groups. However, due to different migration history, cultural patterns and environmental conditions, the results from USA based studies



may not be entirely generalisable to UK ethnic groups. Furthermore, two of the six studies from the USA combined members of different ethnic groups into categories such as ‘Non-white’ or ‘Black’ and ‘White’. This is problematic for two reasons: firstly doing so undermines both the heterogeneity and identity of different ethnic groups. Secondly, the diverse experiences and perhaps cultural values of the different groups which may impact their beliefs about CRC screening are overlooked.

In contrast to American studies, UK based studies tended to feature multiple ethnic groups including people of South Asian origin (Bengali, Indian and Pakistani), African-Caribbean and South East Asian (Vietnamese/Cantonese) origin. Furthermore, the beliefs of ethnic groups of similar origin, such as people of South Asian, were always examined separately and this helped uncover some interesting areas of difference. For instance, Hindu Gujarati participants perceived significantly lower levels of social support for screening whilst Punjabi Sikh participants’ perceived social support was amongst the highest out of all the South Asian groups (Szczepura, 2003b). These findings illustrate the importance of examining differences within groups of broadly similar ethnic origin and not treating them as homogenous groups as this may overlook any cultural differences such as those identified in the above study (Bhopal 2007). Whilst UK studies were very good at examining the variation of beliefs about screening amongst the different South Asian groups, only one study (Szczepura, 2003a) included Black African and Black Caribbean participants. However, this study did not differentiate the two groups and instead referred to them collectively as “African-Caribbean”, thus overlooking key differences in cultural identity, migration history and language that may contribute to different beliefs about CRC screening. This criticism will be addressed in the empirical research undertaken in this thesis where Black African and Black Caribbean groups will be examined separately. As mentioned at the beginning of this thesis, there is very little information on views about screening of African and Caribbean groups in the UK, who comprise a significant proportion of the population of South East London. Thus, the research undertaken in this thesis will address an important

gap by focusing on the views of the local population in South East London who are both ethnically and socio-economically diverse.

A recurring concern with papers that considered beliefs about CRC screening in relation to either ethnicity or SES was the lack of consideration of the other factor. Therefore, it was difficult to ascertain whether knowledge differences attributed to ethnicity for example, were due to ethnic differences or variation in SES such as educational attainment. Although belonging to an ethnic minority background is often highly correlated with low SES, this relationship is not always consistent; assuming so is dangerous as important factors may be neglected (Nazroo, 1998). None of the studies in this review reported including ethnic minority groups of high SES. One study that included ethnicity and SES, however, compared South Asian participants with low SES Scottish participants without giving any SES details of the South Asian group and without stating ethnicity information for the Scottish group (Techer et al., 2009). Nevertheless, there were many similarities in the views of both groups, except for issues regarding religious duty and language barriers that were mentioned by South Asian groups of unknown SES only. In contrast, Scottish participants of unknown ethnicity raised more concerns about the screening process itself (Techer et al., 2009). Whilst information on the area of ethnic differences is important, it is only useful when considered alongside wider social and SES factors, particularly as ethnicity may not always be the reason behind the observed difference (Atkin, Ali et al. 2009).

#### **4.4ii Limitations of review**

The findings of this review should be generalised with caution. Due to different health systems and population groups, the literature focusing on American populations may not be entirely relevant to understanding the beliefs about CRC screening of ethnic and socio-economic groups in the UK. As noted by Elkan, Avis et al. (2007), a focus on the views of people from minority ethnic groups can falsely create the appearance of ‘issues’ for

particular ethnic groups when often there are similar issues and challenges for people from all ethnic groups. Moreover, by selectively reporting key findings it is easy to give the impression that a particular experience is common to an entire ethnic group, when in fact there is considerable variation both between, and within, every ethnic group. The majority of the studies reviewed did not include a comparative group such as respondents from White majority groups, making it difficult to compare majority and minority ethnic groups. The aim of most studies was to report problems and issues regarding CRC screening for particular groups, making it difficult to ascertain how common or widespread such problems were within these groups. One study did, however, try to address these issues by comparing their results for South Asian participants with findings of earlier FOBt pilot studies with White European participants (Szczepura, 2003b). A further limitation is that the views of all ethnic groups were not examined in relation to all of the TDF domains which made it further difficult to draw conclusions about similarities and differences between different groups.

The overall methodological quality of the included papers was modest and broadly similar across the three categories of papers. Papers that focused on SES and ethnicity and SES were slightly higher in quality than papers that focused on ethnicity alone. Common weaknesses across studies included the lack of reliability analyses of data collection instruments (quantitative studies), lack of discussion on the quality of the analytic process (qualitative studies), no consideration of sample size for analytic purposes (statistical power for quantitative studies and data saturation for qualitative studies), lack of explicit theoretical framework (qualitative and quantitative studies) and little user involvement in study design (qualitative and quantitative studies). The study quality tool (Sirriyeh et al., 2011) employed in this review was novel as it allowed the appraisal of quantitative, qualitative and mixed method studies through common and design specific criteria. However, as the quality tool is relatively new, further use by researchers will help validate its usefulness.

This review utilised narrative synthesis in order to analyse and synthesise the results which was useful in enabling the synthesis of both quantitative and qualitative studies. Moreover, the method enabled the structured and detailed exploration of the similarities and differences between different groups. However, the steps involved also made it an unwieldy method to use given the number of papers that were initially retrieved. The robustness of the synthesis may have been influenced by how the review was carried out. A single author undertook the searches and scanned the titles of retrieved papers for relevance. However, abstract selection was undertaken by the author and her doctoral supervisor. Furthermore, a random 10% of full text papers were reviewed and data extraction of a different 10% set of papers was undertaken by the author's supervisor to validate the review process further, with good agreement overall.

Whilst similarities and differences between the different groups have been outlined, a potential criticism of this review is that there is no description of the magnitude of these patterns, through effect sizes for example. It was a conscious decision not to focus on the quantitative data as the majority of studies were qualitative and for the ones that were quantitative, a variety of statistical analytical methods were used and data were not presented in a way that would facilitate comparisons between the different ethnic and SES groups. Thus, the scope of this review is limited to describing the patterns of beliefs across different groups and does not provide information about the significance or strength of certain beliefs over others in relation to CRC screening. A further limitation of this review that is based on observational qualitative and quantitative studies, with self-reported data from participants, is that the causal factors cannot be identified.

The studies undertaken in chapters five and six of this thesis will endeavour to address some of the limitations of existing research. For instance, using the TDF to structure the topic guide and analysis of the qualitative interview study in chapter five, and the development of a questionnaire based on the TDF in chapter six will provide a strong theoretical foundation

to this thesis. Furthermore, all data collection tools including the qualitative interview schedule and questionnaire will be piloted prior to use in order to determine the clarity and appropriateness of questions. In the qualitative study (chapter five), preliminary analysis will be undertaken concurrently to participant recruitment in order to establish the point at which data saturation occurs. Moreover, in the questionnaire survey (chapter six), the reliability of the questionnaire will be statistically assessed and effect size calculations will be undertaken to quantify the magnitude of any differences emerging between ethnic and socio-economic groups.

#### **4.4iii Implications for psychological theory**

The TDF was used as the basis for the synthesis of this review with findings organised according to the theoretical domains. However, the classification of theoretical constructs, as labelled by authors of the original studies, into TDF domains was not straightforward due to the variety in terminology used to describe constructs by different authors. Moreover, it is possible that using a less structured approach to synthesise the findings of this review may have resulted in the findings being interpreted and presented differently, as well as additional factors, not part of the TDF, being uncovered. However, the wide breadth of psychological constructs in the TDF may have mitigated the risk of important factors being missed. Using the TDF not only provided a comprehensive framework within which the beliefs of different SES and ethnic groups could be examined, but also presented another opportunity to test the validity of the theoretical framework in the context of CRC screening. As well as encompassing constructs from a wide range of psychological theories of the determinants of behaviour, a further strength of the TDF was the inclusion of environmental factors, such as trust in doctors as well as some culturally specific beliefs regarding religion.

As demonstrated in Tables 4.2, 4.4 and 4.6, collectively, there was good coverage of the TDF in the findings of this review although coverage within individual studies was much

less. Only two domains: 'Memory, attention and decision' and 'Reinforcement' were not examined by any of the studies in this review. Qualitative studies tended to include more domains than quantitative studies, where the most commonly featured domains were 'Knowledge', 'Beliefs about Consequences', 'Beliefs about Capabilities', 'Emotions', 'Social Influences' 'Environmental Context and Resources', 'Intentions' and 'Optimism/pessimism'. According to these domains, the relevant psychological theory to the findings of this review is the 'Theory of Planned Behaviour' (intentions, beliefs about consequences, beliefs about capabilities and social influences). However, this theory does not include many of the other important domains such as 'Knowledge', 'Emotions', 'Optimism/pessimism' and 'Environmental Context and Resources' that were found to be important in shaping people's beliefs about screening. Therefore, the TDF may be the way forward in terms of its comprehensive coverage of theoretical domains, many of which were found to be relevant to understanding people's views about CRC screening. Future research examining the mediators of the impact of ethnicity and/or SES on CRC screening uptake may thus focus on a variety of psychological factors as possible mediators.

An overwhelming number of studies focused on the 'knowledge' domain findings that the lack of knowledge was a barrier to participating in screening via the FOBt. For instance, in one study (O'Malley et al., 2004) although some participants perceived the FOBt to be distasteful, the majority reported they would still do the test if they had more knowledge about its benefits and procedure. However, these findings are not entirely consistent with previous research which has shown knowledge to be a weak, if not, non-significant predictor across a range of behaviours (Ajzen, Joyce et al. 2011.) Knowledge barriers are likely to exist in conjunction with additional environmental or skills based obstacles to participation in screening. Furthermore, whilst people report that they would be more likely to take part in screening if they had greater knowledge about it, this may not be an accurate reflection of the underlying cognitive processes that drive their behaviour in reality, described as "telling more than we can know" in a seminal paper by Nisbett and Wilson,(1977)

#### **4.4iv Implications for informed choice in screening**

Informed choices about whether or not to undergo screening are those based on good knowledge, consistent with the individual's attitudes and behaviourally implemented (Marteau et al., 2001, see chapter three). To that end, when promoting informed choice, it is important to ensure that people's values and attitudes, positive or negative, are based on good knowledge. For papers that examined ethnicity, knowledge was found to be both high and low in different ethnic minority groups, although the types of perceived benefits/disadvantages of screening tended to be similar across the group, suggesting informed choice may be hampered by low knowledge for some, but not all, ethnic minority groups. For SES, the findings were more consistent: knowledge of CRC and screening was found to be low in low SES groups, as well as ethnic minority groups of low SES. In addition, people of low SES also tended to perceive fewer benefits of participating in screening compared to those of high SES. These findings suggest that socio-demographic differences in uptake of CRC screening, outlined in the introduction of this chapter, may reflect a lack of informed choice. Moreover, the factors inhibiting informed choice seem more likely to be related to SES indicators, such as low educational attainment, which were associated with deficits in knowledge of CRC and screening. Therefore, any intervention aiming to increase informed choice in screening decisions may focus on the way in which information about screening is framed and delivered.

#### **4.4v Implications of the findings and next steps**

The results of this review may have some important implications for understanding screening participation in South East London. The findings illustrate that not all ethnic minority groups view screening negatively as the majority of groups perceived similar benefits of screening and some South Asian participants even viewed screening as part of their wider religious duty to look after themselves (Khan, 2010). However, the majority of UK based studies focused on people of South Asian origin, with only one study (Szczepura,

2003a), including “African-Caribbean” people; the main ethnic minority groups of South East London. As Szczepura, (2003a) did not differentiate the views of Black African and Black Caribbean participants, the extent to which the beliefs about screening of these two culturally diverse groups may be similar or different remains unclear. Moreover, the 27 “African-Caribbean” participants included by Szczepura, (2003a) were all recruited from the West Midlands and there were no references to participants’ SES in the discussion of the findings. This thesis will address this gap in research by separately examining the beliefs of Black African and Black Caribbean people, alongside the consideration of socio-economic factors.

The findings of this review also suggest that differences in SES may play a more prominent role in shaping people’s beliefs about CRC screening. Given the diversity of the population in South East London, researchers and healthcare professionals involved in designing interventions to address the low uptake of screening need to refrain from stereotyping members of particular ethnic groups and, essentially, understand when ethnicity may be making a difference to views about screening and when it does not. Making the materials that accompany screening invitations clear and easy to read would help minimise literacy barriers and some misconceptions about screening. In addition, low SES groups may require further engagement by healthcare professionals to help overcome additional obstacles to making an informed choice regarding screening.

This review has outlined some interesting patterns in the beliefs about CRC screening in different ethnic and socio-economic groups. The next chapter presents the first empirical study of this thesis: a qualitative interview study that explores the role of ethnic and SES factors in people’s views about CRC screening in South East London.



## Chapter Five

### A Qualitative Study Exploring the Factors Affecting Participation in CRC Screening in South East London

#### Abstract

**Aims:** To explore the beliefs of Black African, Black Caribbean and White British people, residing in a socio-economically diverse area of south east London, about CRC screening participation via FOBt using a topic guide based on the Theoretical Domains Framework (Michie et al., 2005).

**Design:** Qualitative interview study

**Methods:** Semi-structured, one-to-one interviews were undertaken with 50 people aged 55 - 74 years, recruited from three GP practices in south east London and representing a range of ethnic groups were fairly even; Black African (n=13), Black Caribbean (n=15) and White British (n=17), with smaller proportions of groups belonging to Black other (n=2) and White other (n=3) backgrounds. Interviews were recorded, transcribed and analysed using framework analysis.

**Results:** There were many similarities in the views of participants from the three main ethnic groups although members of ethnic minority groups were generally more positive about screening than the White British group. Belief types that might serve to encourage screening participation in all ethnic and socio-economic groups included *beliefs about consequences* that screening could save one's life, *knowledge* of someone with cancer, *emotions* including anticipated regret of non-participation if later diagnosed with CRC, *behavioural regulation* where being able to prioritise *FOBt* completion amongst other daily routines appeared to facilitate screening participation. However, there were some notable group differences by ethnicity and socio-economic status (SES). Misunderstanding of the instructions to complete the FOBt in the *skills* domain was a reported obstacle to screening for people of low SES. In relation to ethnicity, White British participants, irrespective of SES, reported physical barriers to FOBt completion such as reduced mobility and were more concerned about particular aspects of the *nature of behaviour*, such as collecting the faecal sample. Additional beliefs, that encouraged screening participation only for members of

Black African and Black Caribbean groups included religious faith, wanting to avoid wastage of NHS resources and a civic duty to participate, as screening was not available in their native countries.

**Conclusions:** This is the first study, to our knowledge, to explore beliefs about CRC screening via FOBT and distinguish between the views of participants from Black African and Black Caribbean groups in the UK. Understanding the views of different groups towards CRC screening has helped to illuminate some of the potential reasons for variable uptake in south east London. However, in order to determine which factors impact screening intentions and behaviour most strongly, quantitative methods are required.

## 5.1 Introduction

Uptake of CRC has been consistently low in South East London, an area with considerable ethnic and socio-economic diversity. As evident from the findings of the systematic review in the previous chapter, the majority of ethnic differences regarding beliefs about screening were attributable to differences in socio-economic status (SES). The reasons behind the much lower uptake of CRC screening in South East London compared to other London boroughs have not been previously studied. Moreover, very little is known about the views of people of Black African and Black Caribbean origin who comprise a significant proportion of the population of South East London, as these were not examined within the original pilots of the national screening programme. Thus, it is presently unclear whether low rates of screening uptake in South East London reflect ethnic or socioeconomic differences in beliefs about screening, or uninformed choices not to participate in screening.

The aim of this study was to explore the views of people living in South East London about CRC screening using an interview schedule based on the Theoretical Domains Framework (TDF; Michie et al., 2005). Previous research suggests that using an interview schedule based on theory and in particular, the TDF elicits a greater number of beliefs than an interview schedule based on research about the behaviour alone (Dyson, Lawton et al. 2011). The broad and comprehensive coverage of theoretical constructs in the TDF was a key reason for its use in this study. In addition, a key objective was to identify factors that inhibited screening participation as well as the factors that promoted screening participation. These beliefs were then used to develop questionnaire items for the survey conducted in chapter six.

## **5.2 Method**

### **5.2.1 Design**

A qualitative design was deemed appropriate due to the exploratory nature of the research and as very little is known about the views about CRC screening of people living in South East London.

### **5.2.2 Participants and Setting**

Recruitment took place at three general practices (one in Lambeth and two in Southwark) that were identified with the help of academic GP colleagues. Practices were located in areas of high area deprivation as denoted by high index of multiple deprivation scores (36.05 Lambeth practice, 52.01 Southwark practice 1 and 29.81 Southwark practice 2) (McLennan, Barnes et al. 2011). Approximately a third of patients registered with a GP in Lambeth are White British and a quarter of patients are from “Black” ethnic minority groups (NHS Lambeth 2009). Southwark is also ethnically diverse where approximately one third of patients are from ethnic minority groups with “Black or Black British” being the largest ethnic minority group (NHS Southwark 2010). The proportion of ethnic minority groups in Lambeth and Southwark is higher than the proportion for London and England (NHS Southwark, 2010).

People of Black African, Caribbean and White British origin, aged between 55 to 75 years attending general practice appointments were approached to take part in an interview. Potential participants were identified by practice receptionists and approached by the researcher prior to, or following GP consultations. The inclusion criteria included people slightly younger and older in age than the age range of the screening programme at the time of recruitment (60 to 69 years) in order to capture the views of people likely to be invited for screening in the imminent future as the age range of the screening programme widens to

include people aged 55 to 75 years. Potential participants were informed about the aim of the study and given a study information sheet to read (appendix 5.1). Participants completed a consent form (appendix 5.2) and a convenient time for the interview was arranged. Those who wanted to spend more time to consider their participation were given the researcher's telephone number and asked to make contact if they later decided to take part.

Participant sampling was purposive to ensure a representative inclusion of males and females and different ethnic group members. General practices were chosen as the sampling frame as they would provide wide access and easy contact with the local population. However a potential limitation of this recruitment strategy is that it only allows accrual of a 'patient population' who are visiting their GP for existing health concerns. It may be that participants who are already 'patients' may have different attitudes, motivations and beliefs about screening than those who do not visit their GP often.

### **5.2.3 Topic guide development**

The interview topic guide was adapted from Francis et al., (2009) who utilised the TDF as the basis of a qualitative interview schedule to understand clinicians' behaviour with regards to blood transfusion. Participation in screening differs from compliance to clinical guidelines as it reflects a behaviour that is a choice compared to a behaviour that is recommended. Moreover, the two behaviours differ further in terms of frequency as CRC screening is a relatively infrequent behaviour, repeated every two years while adherence to clinical guidelines may be required on a daily basis. Furthermore, participation or non-participation in screening only has consequences for the individual whereas adherence or non-adherence to clinical guidelines by healthcare professionals has repercussions for patients. The amendments made to the questions reflected this difference in behaviour. At the time of this study, the TDF had not been validated and contained the following twelve domains, which have since been modified (Cane et al., 2012)

- Behavioural regulation
- Beliefs about capabilities
- Beliefs about consequences
- Emotion
- Environmental context and resources
- Knowledge
- Memory, attention and decision processes
- Motivation and goals
- Nature of the behaviour
- Skills
- Social influences
- Social role and identity

Two domains required further adaptation apart from question wording. The social role and identity domain was adapted to encompass cultural and religious identity and the environmental context and resources domain was adapted as participation in screening is not a daily behaviour, as mentioned above.

Although the TDF has been used to identify behaviour change techniques and more recently to inform understanding of clinician behaviour (Francis et al., 2009), no study to date has applied this approach to understand participation in screening. Moreover, use of this systematic selection of constructs offers comprehensive coverage of several pertinent theories and constructs relating to behaviour and behaviour change and also provides a firm theoretical basis to the study, in line with recommendations from the Medical Research Council (Craig, Dieppe et al. 2008). Using such a theory based approach will not only help uncover the factors influencing uptake of colorectal cancer screening but will also inform the development of interventions to target the key health beliefs identified from the current

study. Three pilot interviews were undertaken to evaluate the effectiveness, relevance and responses to the questions in the topic guide, resulting in some minor amendments to question wording. The final version of the topic guide is included below in Table 5.1. Although the questions appear to reflect a more structured interview, participants were allowed to discuss issues that were not included in the topic guide. Moreover, if any domains had been covered in participants' responses to other questions, these questions were not repeated.

**Table 5.1:** Interview topic guide and corresponding domains of the TDF

Domain	Question
Knowledge	<p>Have you previously heard of bowel cancer, also known as colon, rectal or colorectal cancer?</p> <p>What do you understand about bowel cancer? What do you think it is?</p> <p>What is your understanding of screening?</p> <p>Have you previously heard about the home screening test for bowel cancer...or done it yourself/ know anyone who has completed it?</p>
Nature of the behaviour	What are your thoughts about you doing this test?
Behavioural regulation	<p>What factors may encourage/help you to complete the test?</p> <p>What, if anything, would need to change in order for you to do the test?</p>
Beliefs about capabilities	<p>How confident do you feel about completing the FOB test yourself?</p> <p>Can you think of any difficulties you might have in completing the test?</p>
Beliefs about consequences	<p>What do you think would be the benefits of completing the FOB test?</p> <p>What would be the disadvantages or negative aspects of completing the FOB test?</p>

Emotion	<p>Looking at the test, I wonder what emotions you might feel when this comes through the post? (or for completers: thinking back to when the test came through the post, can you remember the emotions you felt?)</p> <p>And what emotions do you think you might feel when completing the test itself?</p> <p>How do you think you might feel after doing the test?</p>
Environmental context and resources	<p>Is there anything you can think of in your everyday routine that may prevent (and help) you doing the test?</p> <p>If you decide to do the test, would there be any factors preventing you from completing it?</p>
Memory, attention and decision processes	<p>What kinds of things would you think about when deciding to do the test? (or when you were deciding whether to take part in screening, what factors came to mind?)</p>
Motivation and goals	<p>How important is to you to do this test for yourself?</p> <p>How important do you think it is that this type of screening was introduced?</p> <p>How likely is it that you will complete the FOB test when the invitation arrives (again)?</p>
Skills	<p>Looking at the test kit and the information alongside it, what skills do you think you might need to complete the FOB test?</p>
Social influences	<p>What might people close to you e.g. partner, children, and friends, think about you doing the FOB test? (<i>probe – why?</i>)</p> <p>Would their views influence in any way your decision to do the test or not? (<i>probe – why/or why not they wouldn't influence you?</i>)</p>
Social role and identity	<p>Some people have religious or cultural beliefs that might affect whether they take part in (bowel cancer) screening. What are your thoughts about this? (<i>Prompt: would any personal ideas or beliefs you may have influence whether you take the FOB test or not?</i>)</p> <p><i>Separate probe – such as any cultural, spiritual or religious beliefs?</i></p>



### **5.2.4 Procedure**

Interviews were held in a private room in the practice and began with providing participants with some general opening questions to ascertain whether participants were aware of the CRC screening programme and whether they had received or completed a FOBt. Additional questions to explore participants' understanding of CRC and the concept of screening were also asked. A brief standardised description of the screening programme was given to all participants as well as an explanation of how the FOBt is completed, demonstrated with use of a sample FOBt kit and accompanying instruction leaflet. This was to ensure participants who were unaware or unfamiliar with the CRC screening programme received enough information to reflect and respond on their beliefs about screening. All interviews were audio recorded and transcribed verbatim. As interviews were transcribed externally, accuracy of transcription was evaluated by comparing the written transcript with the audio recording, which also aided familiarisation with the data. Following the interviews, all participants were sent a letter of thanks for taking part in this study (appendix 5.3).

### **5.2.5 Measurement of socio-demographic information**

At the end of the interview, participants were asked to complete a socio-demographic questionnaire on age, previous screening behaviour, family history of CRC, educational qualifications, housing tenure, car ownership, employment status and ethnic group (appendix 5.4). Questions regarding educational qualifications, housing tenure and car ownership were then used to derive an individual index of SES, as outlined in chapter two. People who owned their homes, owned a car and had educational qualifications were considered to have the lowest social deprivation (scored as 0). Those who either owned their homes, a car or had educational qualifications were considered to have intermediate levels of social deprivation (scored as 1) and neither owned a home or a car and did not have any

educational qualifications were considered to have the highest level of social deprivation (scored as 2). This combined measure of SES has been previously used in similar research studies (Crockett et al., 2008, Wardle et al., 1999, Wardle et al., 2004).

### **5.2.6 Data analysis**

Interviews were analysed using Framework Analysis (Ritchie and Spencer 1994) and interpreted with a view to highlighting key themes. Framework analysis was chosen as the method goes beyond exploration of themes that emerge from the data and instead, allows data to be used to address specific research questions. Furthermore, the framework method provides a systematic and comprehensive structure within which the emergent themes can be ordered, allowing comparisons of associations both within and between different ethnic and SES groups (Ritchie, Spencer et al. 2003). In addition, framework analysis allows quick and easy access to the original data which supports the transparency of the analysis to others (Ritchie et al., 2003). Although framework categories were determined *a priori* and comprised the domains of the TDF from the interview topic guide, lower order themes emerging within the domains were also examined as the analysis progressed. Transcripts were uploaded into the Nvivo data management programme (QSR International Pty Ltd; Doncaster, Victoria, Australia) and analysed through the following five steps:

1. Familiarisation
2. Identifying a thematic framework
3. Indexing
4. Charting
5. Mapping and interpretation

Firstly, familiarisation involved reading the interview transcripts in order to gain an overview of the content. This phase started whilst interviews were still being undertaken. Four transcripts were read in detail in the first round of familiarisation followed by a further

six transcripts in the second round. For stage two, identifying a thematic framework, the theoretical framework was established *a priori*, as mentioned above. Themes from each transcript were listed and then clustered according to the TDF domain they belonged in (see appendix 5.5 for the themes generated from the first round of familiarisation). The framework was revised and refined throughout the process of data analysis as new themes emerged from the transcripts. In the third stage, indexing, each transcript was coded according to the domains and themes in the framework. In the fourth stage, charting, the indexed data was transported into a chart or grid that was created for each domain of the TDF. In the chart, each participant was represented along a row and each theme was represented by a column. A central chart was then compiled where every domain for every participant was summarised within a single chart. In the final stage, mapping and interpretation, the central chart was examined in order to fulfil the aims set out at the beginning of this chapter and to examine the factors that encouraged participation in screening and the factors that discouraged participation within each domain. Unlike previous studies, ethnic minority groups were not aggregated and were studied separately in light of different cultural patterns that may exist in Black African and Black Caribbean participants that may contribute to their beliefs about CRC screening.

### **5.2.7 Validation of framework analysis**

According to Ritchie and Spencer, (2003), there are two dimensions to ensuring the validity and precision of analysis. The first dimension is internal validity which concerns the extent to which what is claimed to be investigated is being investigated (Ritchie and Spencer 2003). The second dimension, external validity, is the extent to which the identified constructs apply to other groups within the population (Ritchie and Spencer 2003). In this study, a number of steps were undertaken to uphold the validity of the analysis. Firstly, a constant comparative approach was undertaken in order to establish the internal validity of the data. This process involves iterative checking of the emerging themes across different interviews

and between different stages of the same interview (Ritchie and Spencer 2003). In this study, comparisons were made between men and women, members of different ethnic groups and participants of differing socio-economic status. The topic guide was piloted with the first five participants to ensure the questions were relevant and appropriate by the target population. A further validity measure was the independent coding of transcripts to the framework by a second researcher and consensus meetings were held to compare the indexed data. Deviant case analysis by ethnicity and SES was also undertaken to examine any potential differences between the groups and also as a final validation check of the themes. In terms of external validity, the findings of this qualitative study were subsequently triangulated in the questionnaire survey in chapter six.

#### **5.2.8 Ethical considerations**

Ethical approval to conduct this study was received from the NHS Outer North East London Research Ethics Committee (REC reference: 10/H0701/2. Research and Development approval was granted by the NHS Lambeth and Southwark Public Health (R&D reference: RDLAM 527). Support for the study was received from the NHS Bowel Cancer Screening Research Committee (NHS BCSRS). All study approvals can be found in appendix 5.6. In line with the principles of research governance and the British Psychological Society's code of conduct, fully informed signed consent was sought from all participants. The right to withdraw from the study at any time was highlighted to participants and a full debrief was given at the end of interviews. Confidentiality of data and protection of participants' anonymity was ensured by storing data securely and changing all participant identifiable details within interview transcripts. As the researcher did not have any access to participants' personal and medical information, reliance was on GP practice staff to ensure no one was approached inappropriately, such as those who have been recently diagnosed with cancer. Such patients were not approached to participate in the study in recognition of the treatment and personal demands they may have been experiencing. People with known

hereditary bowel cancer risk syndromes such as familial adenomatous polyposis, were also advised not to take part as they were likely to be undergoing regular bowel cancer checks due to their increased genetic risk. Participants expressing a keen interest in undertaking screening were provided with information from the national screening programme on the steps to take. Any participants who were concerned about their risk of colorectal cancer or symptoms were advised to consult their GP at the earliest opportunity.

## 5.3 Results

### 5.3.1 Participants

Fifty people (21 women and 29 men) aged 55 to 74 years, took part in this study. Reasons for non-consent generally included a lack of interest or lack of time to discuss the study. One participant agreed to be interviewed but later withdrew as she did not want to sign the study consent form. Three further participants withdrew following consent due to personal commitments; two due to deteriorating health and one participant was going on holiday and a convenient time for interview could not be arranged. Participants' demographic details are displayed in table 5.2, below.

**Table 5.2: Summary of socio-demographic details of interviewed participants** N (%)

Gender	Men (mean age 65.61 years, S.D. 4.73)	29 (58)
	Women (mean age 65.13 years, S.D. 4.54)	21 (42)
Ethnicity	Black African	13 (26)
	Black Caribbean	15 (30)
	Black Other	2 (4)
	White British	16 (32)
	White Other	4 (8)
Social deprivation (SD) score*	High SD	17 (34)
	Intermediate SD	22 (44)
	Low SD	10 (20)
	Missing	1
Self reported screening status	Completed	18 (36)
	Declined	7 (14)
	Not invited	19 (38)
	Invited but not yet completed	5 (10)

	Completed FOBt outside the CRC screening programme	1	(2)
Marital status	Single	16	(32)
	Married/civil partnership or cohabiting	19	(38)
	Separated or divorced	9	(18)
	Widowed	6	(12)
Level of education*	No formal qualifications	19	(38)
	High school education $\leq 16$ years	3	(6)
	High school/college education $\leq 18$ years	7	(14)
	University education $>18$ years	11	(22)
	Other (e.g. nursing qualifications, trade certificate)	9	(18)
	Missing	1	
Occupational status*	Full time employment	5	(10)
	Part time employment	6	(12)
	Unemployed	3	(6)
	Retired	30	(60)
	Retired early	3	(6)
	Other (e.g. voluntary work)	2	(4)
	Missing	1	
Time as UK resident	From birth	17	(34)
	$<5$ years	1	(2)
	6-15 years	7	(14)
	16-30 years	6	(12)
	$>31$ years	19	(38)

\* denotes missing values where information was not provided

As evident from table 5.2, the majority of participants were within the age range of the CRC screening programme. However, quite a few participants reported they had not been invited for screening at the time of being interviewed, despite being within the age range. Overall, there were very few people who had reported they decided not to take part in screening, all of whom were of White British origin. Participants were fairly evenly dispersed across the three main ethnic groups, with a small proportion identifying themselves as ‘Black Other’ as they were of mixed ethnicity, or ‘White Other’ as they were of mainly of White Irish or European origin. A social deprivation (SD) score for each participant was also assigned from the socio-demographic information they gave (housing tenure, car ownership and educational qualifications). The majority of participants were within the intermediate social deprivation category as they either had an educational qualification or, owned their home or vehicle. There were noteworthy inter-group differences with regards to SD score whereby

the majority of African participants were in the intermediate category due to lack of home ownership although most had an educational qualification to at least tertiary level. Conversely, the high and low SD categories comprised an even mix of Caribbean and White British participants, albeit smaller proportions. Representatives of each of the ethnic groups were present across all SD categories which allowed the exploration of both the independent and combined contribution of ethnicity and socio-economic factors to people's beliefs about screening.

### **5.3.2 Findings of framework analysis**

To aid interpretation of the data, the charted data was organised firstly by ethnic group and then by participants' social deprivation (SD) score. Furthermore, as the framework itself comprised the construct domains from the interview schedule, this also aided interpretation as the beliefs and themes emerging from the analysis and associations between them could be interpreted with the underlying theoretical construct in mind. The following analysis addresses the research questions posed at the beginning of this section reporting specifically the factors that encouraged participation in screening and the factors that made people feel reluctant to take part which are structured according to domains of the TDF. Factors unique to a particular ethnic or socioeconomic group are also highlighted. Participants are referred to by their Study Number, followed by ethnicity, gender, self-reported screening status and SD score.

#### **Beliefs about consequences**

Participants discussed the 'consequences' of getting CRC as well as the consequences and benefits of undergoing screening for themselves, which mostly encouraged participation in screening.

### *Helping oneself*

This theme emerged as a consistently reported facilitator of screening. Taking part in screening was seen by participants of all ethnic and SES backgrounds as a way of protecting one's own interests and keeping healthy, a particular priority as participants reported feeling more susceptible to illness as they were getting older. This was also related to the common belief amongst participants that cancer, in general, was a hidden disease, developing silently and suddenly inside the body. Once again, this belief was endorsed by participants of all ethnic and SES backgrounds.

*“For me, for protect my interest from sickness, short life, long life, that's what it's there for. To protect my interests. Yes that's how I see it.” (P9, African Male, 66 years, not yet invited for screening, SD1)*

*“So trying to put something right that unfortunately goes wrong. I have had nothing going wrong at the moment in that respect. Maybe as I get older I'm getting worse. Now unfortunately they don't make too many spare parts!” (P41, White British, male, 63 years, completed screening, SD 2).*

The consequences of screening were also perceived to be a direct benefit for oneself for the majority of participants across all ethnic and SES groups. Many participants believed that if cancer was present, early detection via screening would result in more successful and “light” treatment, fewer complications, would prolong, and ultimately save, one's life. Related to this latter belief about the efficacy of screening was a common misunderstanding that screening was a preventative initiative that would help people avoid developing cancer. Once again, beliefs about the role of screening in cancer prevention were endorsed by participants of all ethnic and SES backgrounds.



*"I believe if they send you it, you should do it because it saves lives as far as I'm concerned...to me it's a choice, live or die basically..." (P17, White British, female, 56 years, not yet invited for screening, SD 2).*

*"...anybody at all can attack by cancer, anywhere, any place, any time. So if I'm given this opportunity, I have to hold it and did it with confidence, so that if I'm getting this cancer, it can be prevented". (P37, African, female, 63 years, completed screening, SD 1)*

*"It's a good idea and as a matter of fact it's a very good idea...find out if there is something wrong before it's too late, because if you leave it too late, then you ain't going to get the treatment you're supposed to get. You know, you're not going to get cured, but you're going to get cured late and you might have to take heavier treatment than if you started when from earlier." (P42, Caribbean, male, 57 years, not yet invited, SD 2).*

Another benefit of screening mentioned by all participants of all ethnic and SES backgrounds was the opportunity to gain reassurance that one did not have CRC/bowel cancer. Repetition of screening every two years provided further reassurance to participants as they knew they would be monitored to ensure there had been no changes. In essence, if one wanted to know whether one was healthy or not, then taking part in screening was the only way to find out. This latter belief corresponded to the 'Motivation and Goals' domain of the TDF.

*"Well I think it would, it would be important, then it would give peace of mind that you haven't got anything at that time, but you can just keep, you know, in fact you're in a programme, and again if something happens the next time, it will be picked up earlier." (P4, White British, female, 64 years, not yet invited, SD 0).*

*"The benefit of doing the screening is to give you a clear mind...and a confident feeling to know that for the moment you are clear". (P50, Caribbean, male, 67 years, completed screening, SD 1)*

However, White British participants of high SES expressed greater doubts about the general effectiveness of screening, chance of false positive results and whether screening was entirely beneficial to individuals. Moreover, one ‘White Other’ participant of high SES did not perceive any benefits of screening as he did not believe there was a “cure” for cancer, which discouraged participation in screening.

*“So a little bit of scepticism about screening, I was by and large thinking if it’s done it will be worked out that on balance it’s worth doing and worth the spending the money on. And some screenings not actually showing the condition as well, it showed something else, factors which may lead to the condition. There’s various things in my mind that are not clearly logged, but some doubts about screening.”*  
(P5, White British, male, 60 years, not completed, SD 0)

*“...if there was a cure for cancer, you know, I might take it up and certainly do the test and have a treatment for it and be not so worried about it. But there isn’t a cure, I’m not aware of one so it’s pointless doing it then.”* (P29, White Other, male, 57 years, not yet invited, SD 0).

### *Perceived risk*

This theme appeared to both encourage and discourage participation in screening. In the quotation below, P52 was keen to take part in screening as he did not see his GP regularly and had some doubts about his health. Screening thus presented an opportunity to gain confidence about his own health, by receipt of a negative result, and peace of mind, that he did not have cancer.

*“...I was very interested, I find it very interested and I was very glad when I sent mine, because there was some doubt within me own self because the way I usually feel sometimes, and I don’t visit my doctor very often and so forth, so I didn’t sure whether I was...”* (P52, Caribbean, male, 72 years, completed screening, SD 2).

Conversely, for P29, the lack of bowel related symptoms was associated with a low perceived risk of CRC, signifying that screening was not needed.

*“I don’t have any bowel problems, no pains, no physical pains, so, you know it would be pointless for me to do it...just one less worry, basically” (P29, White Other, male, 57 years, not yet invited, SD 0)*

#### *Helping others*

As well as helping oneself by taking part in screening, the majority of participants in this study also believed that their participation would benefit others. This theme also primarily encouraged participation in screening. The perception of helping others appeared to be intertwined with beliefs about the purpose of screening; whilst some participants believed screening was like having a regular check up, quite a few African and Caribbean participants in the intermediate and low SD groups thought it was a form of medical research. To that end, taking part in screening was perceived to have benefits for society in general as one’s contribution could advance science, and possibly help find a cure for CRC/bowel cancer.

*“Well I did it to help the medical research...I was a bit annoyed but I wanted to help the medical research” (P1, African, male, 67 years, completed screening, SD 1)*

*“...after I’ve done the screening, if you can use it to help other people, I think it, I think it would be great... I have a family coming up, my next generation and when I’ve done this screening, if one of them – hoping not – but if one of them might sick in that way, might be hope you can help them.” (P44, Caribbean, male, 71 years, not yet invited for screening, SD 2)*

African and Caribbean participants also cited benefits of them participating in screening for doctors and healthcare staff as early detection would help them to manage the disease more easily.

*“I can’t think of any disadvantages at all. I felt that the more people do it, the more encouraged all the scientists are to go on deeper and deeper into the treatment of such a disease.” (P46, African, female, 64 years, completed screening, SD 1).*

*“But when them send that to you – for instance now, they send that to me and I got through the test and they could send back and say I’m alright. Yes, so if I’m alright, I don’t have to go to them and say I’m sick with this, I’m sick with that. They find out for themselves. And then instead of me would have make coming to them, they have other patients that they need to look after.” (P52, Caribbean, male, 72 years, completed screening, SD 2).*

An underlying motivation for many African participants across all SES categories was the need to complete screening for the sake of their families; be it to avoid distress for partners and children if they were later diagnosed, or a desire to live and see their grandchildren grow up. Thus a decision to take part in screening was not just focused on the self but also contained an element of responsibility towards others. A similar reason was given by a White British participant in the intermediate SES group, illustrated in the quote below.

*“I suppose really it’s for your own peace of mind, isn’t it? Plus the family, you know. I’m still married and have a couple of kids and grandchildren, you know. So it’s not only you that will sort of go, it’s going to affect the family as well.” (P21, White British, male, 73 years, not yet invited for screening, SD 1).*

On the other hand, P27, a White Irish male, in the quotation below mentioned he was less inclined to take part in screening because he was a single person. Had he had a family, he would “have to participate for them”. This belief also related to the ‘Social Influence’ domain.

*“Being a single person, you know, but if I was a family man, it would be a different case obviously, I’d look into all these sort of things, you have to for your kids as well...” (P27, White Other, male, 62 years, completed screening, SD 1)*

## **Beliefs about Capabilities**

### *Confidence*

Participants' confidence in their ability to complete the FOBt was overall high in both those who had previously participated in screening as well as those who had not yet been invited, irrespective of ethnicity. However, participants of lower SES reported greater difficulties with understanding instructions for completion, as discussed later in the 'Skills' domain.

*"I was confident enough to do it. I did it and didn't need help. So therefore I feel myself being confident. Very confident to do it...I followed the instructions no problems." (P40, African, male, 71 years, completed screening, SD 1)*

Moreover, some participants of lower SES who had previously completed the FOBt also reported difficulties with collecting the first faecal sample but this became easier as the remaining samples were collected.

*"The first day I found difficult. But it was alright the second day. And the third. Because it was the first time I'd done it, like, you know." (P22, White British, male, 66 years, completed screening, SD 2)*

For participants who had not been invited or not responded to their previous screening invitation, the majority reported feeling confident about their ability to complete the FOBt after seeing a sample FOBt kit and instructions leaflet. Although a sample FOBt kit and instructions leaflet was shown to all participants during interviews, it is possible that this influenced the beliefs about capabilities of people who either had misconceptions about the procedure of the FOBt or those who had no previous knowledge about it, as illustrated in the quotes below.

*“Well, to be honest with you, I didn’t know it was going to be so easy, you know, this seems like it’s quite easy to deal with, you know.” (P19, Caribbean, male, 55 years, not yet invited for screening, SD1)*

*“First thoughts are, erm, well it’s easy enough to do, isn’t it? It’s not as if it’s difficult and it’s not as if you’re scooping huge wedges of faeces and sticking them in things. I did have that as a sort of a brief thought when I got the thing, was about sending stuff through the post. I mean so I didn’t obviously didn’t read into it carefully at all, because it’s actually quite different to what I’d imagined at the beginning. That’s not what stopped me by the way, I still would have done it, but it’s even easier than I had envisaged.” (P26, White British, male, 66 years, not completed, SD 1)*

Only one participant out of the seven who had declined their previous screening invitation reported a lack of self-confidence in completing the FOBt although the test itself was perceived to be relatively simple in comparison to childbirth. This lack of self-confidence appeared to be related to the nature of the test that required the collection of a faecal sample.

*“Not at all confident no, not one little bit. I thought about it, but went ‘no...think you’ve had babies and all of this and all of that and you can’t do a simple thing, but it’s just the thought of it” (P7, White British, female, 68 years, declined screening, SD 2).*

## **Knowledge**

The majority of themes within this domain appeared to encourage participation in screening.

### *Previous cancer or knowledge of others with cancer*

Participants across all ethnicities and SES situations often gave knowing a close family member or friend who had died of cancer and not wanting endure the same pain and suffering themselves that they had witnessed the people close to them experience as a reason for participating in screening.

*“I had a very close friend who died of it, we were for many years close. So, and erm, I saw the whole process as such, I was with him throughout the period until he passed away... When you’ve seen someone close going through that process, then you understand why you have to fill in those, do those tests.” (P33, African, male, 60 years, completed screening, SD 0).*

*“Well I was thinking, going back to this lady again, I wouldn’t want to suffer like she did if I had something like that. And I wouldn’t cope, I don’t know how I would cope if I had cancer. But, I think I’d be really depressed about how long have I got and how far advanced it is” (P22, White British, male, 66 years, completed screening, SD 2)*

Where some participants reported feeling susceptible due to a family history of cancer, for others, it reinforced the perception that cancer was a nasty illness that could “creep up” on them at any time. Four participants had also previously suffered with cancer themselves and thus believed they were at increased risk of getting CRC/bowel cancer so were keen to be screened. Thus, people’s knowledge, by way of previous cancer experience and family history, appeared to influence their perceived risk of CRC, demonstrating overlap in the ‘Knowledge’ and ‘Beliefs about Consequences’ domains.

*“I feel okay, because I was getting worried, you know, because I’ve got cancer before in the kidney and I only have one kidney, so I gets worried, and I don’t know what’s exactly going to happen, you know.” (P13, African, female, 68 years, invited but not yet completed, SD 2)*

#### *Previous cancer screening*

For women of all ethnic and SES backgrounds, a stronger inclination to take part in CRC screening was underpinned by the belief that the programme was just like the existing breast and cervical cancer screening programmes they were already, or previously, participating in. Moreover, knowledge of cancers detected through screening also appeared to add weight to

participants' belief in the efficacy and importance of screening for CRC/bowel cancer. For instance, P17's sister was recently diagnosed with breast cancer following a routine screening mammogram and P49 was diagnosed with prostate cancer following a self-requested prostate specific antigen (PSA) test.

*"Well it's the same with going for a mammogram, isn't it?" (P24, White British, female, 63 years, declined screening, SD 1).*

*"I don't know if it's because of Mary because she's got it now, and she went for her breast screening. So it might have, 'Oh they've caught Mary, so I might do this now,' because it's early, do you know what I'm trying to say?" (P17, White British, female, 56 years, not yet invited for screening, SD 2).*

*"I'd been hearing about PSA, PSA, what is it? He said 'Oh let's look at your age, okay let's try and see, you know, if we see how,' I went and did blood test. Within three days he (doctor) called me..." (P49, African, male, 68 years, not yet completed due to ongoing prostate cancer treatment, SD 1).*

Conversely, White British men appeared to have less knowledge about the CRC screening programme and the concept of screening itself.

*"Very little because I've not had to have any screening tests or anything like that. So it's very little, it's just a word" (P23, White British male, 62 years, declined screening, SD 1).*

#### *Knowledge of other cancers*

Several African and Caribbean men, of varying SES, mentioned they were aware of prostate cancer and discussed their concerns about risk of the disease. However, African and Caribbean men admitted they knew very little about CRC/bowel cancer and queried whether



the two types were related. Nevertheless, this heightened awareness of prostate cancer appeared to promote positive views about CRC/bowel cancer screening for men.

*“...I know about cancer, but I didn’t really have any understanding about bowel cancer that would be different, I was considering prostate, and the ordinary cancer, like I didn’t really know about bowel.” (P52, Caribbean, male, 72 years, completed screening, SD 2).*

#### *Previous bowel problems*

Another key motivation for screening for the majority of White British participants was the experience of previous bowel problems which implied to participants that they were at elevated risk of getting CRC/bowel cancer. Participating in CRC screening was therefore another opportunity for keeping check on a pre-existing problem and gain reassurance it had not developed into cancer. Problems included diverticular disease, irritable bowel syndrome, haemorrhoids as well as the presence of faecal blood, investigations of which required participants to have colonoscopies or complete the FOBt independently of the screening programme (P6). One participant who had received his FOBt at the time of interview but had not completed it was waiting for his bowel health to improve to ensure an accurate result. Bowel related problems were not frequently reported by Black African or Black Caribbean participants.

*“I was told that, about bowel cancer because of suffering with diverticulitis of the sigmoid colon. So I was told there was a possibility, if anything goes wrong there, that could cause cancer, in that respect.” (P41, White British, male, 63 years, completed screening, SD 2).*

*“The basic reason is that the condition of my bowel movements varies anyway. I have a tendency to irritable bowel syndrome... so, and I thought I, my sort of bowel health was not particularly good at the time, so I thought I’d wait*

*until I felt it was better before I took the test.” (P5, White British, male, 60 years, invited but not yet completed FOBt, SD 0)*

On a related note, screening via the FOBt was more acceptable to participants who had had investigations such as a colonoscopy as it was perceived to be less embarrassing and intrusive than having a colonoscopy.

*“I’ve had one of those (colonoscopy)...once again I don’t know why I did it. I did it privately, and I’ve got diverticular disease, that was discovered. So that was a bit of a problem, like doing it, but no that was, I just thought it was worth doing” (P20, White British, male, 68 years, completed screening, SD 0).*

#### *Need for more awareness*

A repeated and clear message across interviews with participants of all ethnic and SES backgrounds was the need for prior awareness of the CRC screening programme and understanding of the benefits of completion. The majority of participants reported they knew very little about CRC/bowel cancer and only became aware of the screening programme on receipt of their invitation. As a result the screening invitation came as a surprise to those participants who were not previously aware of the screening programme. However, those who were previously aware of CRC screening accepted their invitation because it was expected.

*“I wasn’t familiar with this one, so I don’t know. It’s more of the ‘don’t know’ factor. I didn’t expect to get a cancer screening kit at sixty. I hadn’t heard about it.” (P5, White British, male, 60 years, not completed, SD 0).*

*“Well my sister told me about it, so I know what it was. She lives up in Leeds then, and they did it and it come back fine. So, and it came, and I knew what it was and what to do, you see.” (P11, Black Other, female, 69 years, completed, SD 2).*

## Social influence

Related to the need for more awareness of screening as discussed above in the ‘Knowledge’ domain, was the promotion of screening by GPs. Participants of high SES questioned why screening was not more widely promoted in media campaigns or GP surgeries like initiatives such as flu immunisation, as this was seen to encourage more people to take part in screening.

*“But the question is not done at the GP, it’s not mentioned when they go to the GP, ‘Please do your tests, bowel cancer can catch-up with anybody.’ ...So it could help by the GP’s place, if the reception tells you, or even if the GP tells you, you could be a tremendous help, you know, to say – ‘Have you had this form? Please do it.’ That’s all, that’s all they need. There’s no problem in that then and a way of getting people to do it. I would like to have the statistics that people around here don’t do it, but who tells them, who encourages them? No one. It comes through the post, that’s the end of it...It’s good to just ask them or remind them to do it. You know, just like they remind everyone to take their flu jab.” (P33, African, male, 60 years, completed screening, SD 0).*

However, men on the whole, irrespective of ethnicity and SES, were less inclined to discuss CRC screening with their GP in the absence of a health problem. In contrast, several women had consulted, or were planning to consult their GP or practice nurse for an explanation on how to complete the FOBt. In terms of approval of screening by participants’ close family and friends, virtually all participants reported that screening would be acceptable to their significant others. However, several participants reported some influence of family and friends in their screening decisions. Aside from participants who had been informed about screening by their family and friends (P4, P11), some had also more explicitly been encouraged to complete the FOBt by family members. In the quotes below, one participant’s sibling advised him to complete the FOBt whereas another participant’s sibling advised him not to.

*“Some people are very good at these sort of things. My sister is. I was going to sling it in the bin and she said, ‘James, no, no, you must do it’,” (P27, White Other, male, 62 years, completed screening, SD 1).*

*“Well, I think I did mention it to my older sister. She said, ‘Oh don’t worry too much about it’,” (P2, White British, male, 63 years, declined screening, SD 2).*

## **Emotions**

Beliefs in this domain appeared to encourage and discourage participation in screening.

### *Anticipated regret*

Regardless of ethnic group, gender or socio-economic position, the majority of participants cited anticipated regret at not completing screening and later being diagnosed with CRC/bowel cancer as a strong motivation for taking part in screening. Here participants also discussed the consequences of late detection including advanced disease, more pain and suffering, and eventual death. Screening was not only viewed as offering people hope of survival or a “chance”, it was also a way of potentially mitigating both future disease complications and emotional distress.

*“Oh yes, the disadvantage is that if you don’t do it. And God forbid you later had it detected, you feel bad and feel disappointed in yourself.” (P34, African, female, 65 years, not yet invited, SD 0)*

*“It’s no good waiting until you’ve got it, and then say, ‘Well actually, if I’d done this earlier,’ it’s too late then isn’t it...” (P21, White British, male, 73 years, not yet invited, SD 1).*

### *Fear*

Although this theme related to the ‘Emotions’ domain, beliefs appeared to be based on other domains, such as the ‘Beliefs about consequences’ of cancer. Overall, fear of CRC and fear

of the potential outcomes of screening such as a positive result, discouraged participation in screening for White British participants of all SES backgrounds but not for participants from other ethnic groups. Whilst some participants feared a cancer diagnosis, others who were discouraged reported the stigma of cancer and feared ridicule if they discussed screening with others.

*“...I don’t want to do it voluntarily...I suppose I’m scared of cancer...just one of those diseases that people with are shunned” (P23, White British male, 62 years, declined screening, SD1).*

As mentioned above, fear beliefs were influenced by beliefs about the consequences of cancer with many participants believing cancer was a serious and deadly disease that could occur at any time. Moreover, knowledge of friends or family members who had died painful or distressing deaths as a result of cancer further contributed to participants’ fear of cancer.

Participants who were afraid of getting a positive result preferred not to know whether they had cancer or not and did not want to voluntarily seek out any problem (P23 and P30).

*“I know this is a neutral test, but as I said, I don’t want to go down the road of sort of cancer treatment and cancer and all that it involves, because generally speaking, I’d say I’m quite healthy, and I’d rather stay – I mean if I suddenly get sick, like I had today, you know, and I think something gets a bit out of the ordinary, then I will go to the doctor. But I don’t want to sort of do it voluntarily, you know. I suppose I’m scared of cancer really basically. And no news is good news.” (P23, White British male, 62 years, declined screening, SD 1).*

In contrast, Black African and Black Caribbean participants of all SES backgrounds along with some high SES White British participants reported no fear or embarrassment of screening.

*“I just think, well it’s nothing to this, there’s nothing embarrassing or scary like that, with this, it’s just a simple little thing, you just put it on there and cover it up and that’s it.” (P11, Black Other, female, 69 years, completed, SD 2)*

### **Social role and identity**

Except for one participant, on the whole, beliefs in this domain appeared to encourage participation in screening.

#### *Religious faith*

In response to a question in the ‘social role and identity’ domain that explicitly asked whether participants’ religious or cultural beliefs would affect whether or not they took part in screening, participants across all ethnic and SES groups reported that religion and health were two separate entities and that one would not infringe upon the other when contemplating CRC screening. Religious faith overall encouraged screening participation for Black African and Black Caribbean participants holding either Christian or Muslim beliefs, as screening was seen as a way of helping themselves. Moreover, those that thought they may get a positive result were not disheartened as they believed God would help them in case they had cancer.

*“God is above everything...the Bible says God help those who help themselves and by helping myself, is by coming to you to examine me to see if there is any problem and then if, the master God will be able to assist” (P39, African, male, 63 years, completed screening, SD 1).*

*I’m a Muslim, but I can do anything for my health...That doesn’t affect religion, belief, or not. That seem like nonsense, because if you believe in something, why don’t you believe in something to make you get well? (P13, African, female, 68 years, invited but not yet completed, SD 2).*

Religious beliefs impacted the screening decision of one White British participant of low SES who reported not taking part due to the FOBt containing the term ‘occult’ which had satanic/demonic connotations for her.

*“I don’t want to be messing around with anything that’s got anything to do with the occult...to me it brings up Satan and demonic things and, you know, and the bowels are very significant, you know, really, in the spiritual world” (P30, White British, female, 60 years, declined screening, SD 2)*

For two participants: one Black African person and one Black Caribbean person, religious faith was linked to beliefs about perceived risk of CRC. As illustrated in the quotation below, one participant believed she would not get CRC with God’s grace which discouraged her to participate in screening. However, by the end of the interview, the participant below (P34) had changed her viewpoint and reported she would participate in screening when she was invited as the misunderstandings she held about the procedure and amount of faecal sample required were now clear. This suggested that misunderstanding of the procedure of the FOBt rather than faith in God was the reason the participant was initially reluctant about undergoing screening.

*“I believe that by the grace of God, I will not go through such illness. So I believe nothing as such will happen to me, because I have God who is taking care of me. So I don’t want the screening and all that, I don’t bother” (P34, African, female, 65 years, not yet invited, SD 0).*

*“...you tell yourself, whatever happens now – with some people - me personally, whatever happens now, it’s in God’s hands... I think they wouldn’t mind if they start seeing changes and that, and a test has to be done. But otherwise, I don’t know if people would just – well that’s how I feel, it wouldn’t be everyone” (P15, Caribbean, female, 74 years, not yet invited, SD 1).*

### *Civic duty*

A repeated theme underpinning Black African and Black Caribbean participants' positive views about screening, regardless of SES, was a sense of 'civic duty' to take part in screening because not participating would be a waste of the NHS' time and money. Closer examination of the data highlighted that White British participants of high SES also shared a similar perceived responsibility to participate in screening. However, for Black African participants in particular, screening was perceived as a privilege or a "help" and something that was not available in their native countries. The NHS was particularly valued as it was a free service that did not discriminate between the rich and poor unlike the complicated and expensive health insurance policies of their country of origin.

*"Those of us who have the privilege of being in this country, are lucky with the care and technology. Where I come from, Nigeria, you don't have these. People dying of one thing or the other...the state doesn't have any provision for them, so they die."*

*(P46, African, female, 64 years, completed screening, SD 1).*

*"I think it's very important because it will save a lot of lives. And would save money in the long run."* (P4, White British, female, 64 years, not yet invited, SD 0).

An underlying sense of obligation to take part in screening was apparent for many African and Caribbean participants of high, intermediate and low SES, with connotations of a duty to abide by the rules of the country they were now living in. This once again, related to the 'Environmental context and resources' domain.

*"But, you know, we are into different country, so we have to – they say when you go to Rome, you have to do what the Romans do!"* (P16, Caribbean, male, 67 years, started FOBt but told to not continue, SD 2).

*"...I know within myself that if people want to help you in this country, they say "do this", you must do it, that's why when they send this specimens, this thing to me to*



*send my specimens, I did it orderly, I send it and I'm happy that they give me feedback that everything was good.” (P39, African, male, 63 years, completed screening, SD 1).*

One participant in particular (P1) reported taking part in screening only after the receipt of the reminder letter which suggested to him that screening was mandatory. However, the majority of participants accepted screening on the basis it would not be implemented if it was not going to benefit people and thus there was no harm in participating.

*“Well I think in the beginning I felt like... not concerned, it's not for me, it's a waste of time, and I put it to one side, but a few weeks later is a letter from the hospital telling me to send my sample. And I thought, my goodness, this is going to be like a compulsory.” (P1, African, male, 67 years, completed screening, SD 1).*

### **Environmental Context and Resources**

Factors that encouraged screening participation and beliefs that discouraged participation were included in this domain.

#### *Free service*

An encouraging factor specific to African and Caribbean participants of high and low SES backgrounds was that screening was offered for free. This factor was not mentioned by White British participants of any SES background.

*“It don't cost you nothing. It's not a problem. So I don't know why people won't send them back.” (P42, Caribbean, male, 57 years, not yet invited for screening, SD 2).*

*“...you don't know whether you have it or not, it ain't costing you nothing to take a test” (P31, Caribbean, male, 73 years, not yet invited for screening, SD 0).*

### *Other priorities*

For the participants who did not complete the FOBt when they had been invited for screening (n=7 White British participants from a range of SES backgrounds) impeding factors included existing physical or mental health problems, being too busy or stressed at work, as well as caring for an elderly parent, thus deeming CRC screening as a low priority.

*“I think the reasons that I didn’t get round to doing anything about it were several and one is that, at the time that I received it, I was working and very busy. But as well as working, I’m also coping with illness which eventually occasioned my early retirement. I had a triple heart bypass and I developed osteoarthritis and I’ve had knee and hip replacements done and I’m going to have another hip replacement. And so I felt, you know, I had enough of medical doings without this as well”. (P14, White British, male, 62 years, declined screening, SD 0).*

*“Well I did get a screening test through the post some years ago, but my circumstances at the time, I didn’t get round to dealing with it, because I was caring for my mother who had severe dementia. So my entire time was full of doing that, so I just left it to one side, and didn’t bother with it.” (P24, White British, female, 63 years, declined screening, SD 1)*

### *Environment*

As well as maintaining privacy during FOBt completion, having adequate space to complete the test was also perceived as an important aspect of the environment. Whilst the majority of participants preferred to complete the FOBt at home, one participant mentioned he would prefer to complete it at work as he could use a disabled toilet that would allow extra space to complete the test comfortably.

*“I’d probably have to do it in work or something like that... at least they’ve got disabled toilet, so you’ve got plenty of places where you can move around the toilet. So I think that would help.” (P18, White British, male, 64 years,*

*not yet invited, SD 2)*

### **Nature of behaviour**

Although this domain does not feature in the most recent validated version of the TDF (Cane et al., 2012), it was part of the framework when these interviews were conducted. There were some issues that were specific to the FOBt that both inhibited and promoted participation in screening.

#### *Convenience*

Participants across all ethnic and SES groups thought that a positive aspect of CRC screening was that it could be conveniently completed in the privacy of one's own home.

*“It’s not like you’re going to sit down and have a long wait, you’re doing it at home, at the time that suited you... this is more convenient.” (P43, Caribbean, female, 72 years, not yet invited, SD 2).*

#### *Faecal sample*

Collection of a faecal sample, an integral part of the FOBt, was an obstacle to screening for some White British participants across all SES categories. Participants were concerned about potential smell, lack of hygiene as well as the mess that completing the FOBt may entail. For one participant (P7), repulsion towards the procedure was associated with lower willingness to complete the FOBt, and for another (P30), posting faecal samples was unacceptable.

*“And I think I have to say that, that the fact that it involved, you know, sending off faeces, for example, didn’t help, because it’s, I think that one would have to be quite sort of, you know, committed and interested to do that.” (P14, White British, male, 62 years, declined screening, SD 0).*

*“...all that messing about. I know you shouldn’t think like that but oh, I couldn’t face it!” (P7, White British female, 68 years, declined screening, SD 2).*

*“You know, putting me bits and pieces in the post, it’s a very private thing. It’s to do with the emotions, the bowels”. (P30, White British, female, 60 years, declined screening, SD 2).*

However, Black African and Black Caribbean participants, in contrast, were not deterred or disgusted by the procedure of the FOBt. Instead, they viewed collection of the faecal sample as a natural behaviour and equated it with other medical tests or procedures such as taking daily insulin. One Black African participant of high SES further justified the naturalness of the FOBt procedure by comparing it to the traditional practice of burying faeces in the ground in the absence of toilet facilities.

*“...because generally those who live abroad, look pass faeces in a piece of paper, go away, dig it down and bury it. So I don’t see what’s the difference, that’s for those who live in the rural areas, where there are no things like modern built up toiletry and things like that. So some of them dive in the bush, so it’s still the same thing, you know. (P33, African, male, 60 years, completed screening, SD 0).*

Another Black Caribbean participant preferred the discreteness of the FOBt to providing a sample in a jar, which was associated with greater embarrassment.

*“I hand it over the counter. You know what’s in it so you feel a bit embarrassed. But you do this and you’ve got a post box, you don’t feel embarrassed about it...” (P44, Black Caribbean male, 71 years, not yet invited for screening, SD 2).*

### **Behavioural regulation**

Beliefs in this domain facilitated screening by enabling participants to plan and prepare how they would complete the FOBt. This was mentioned by participants across all ethnic and SES groups who reported they had completed the FOBt.

*“I mean when I first got it, I just thought, ‘How the hell am I going to go about this?’ You know, you have to think, ‘How do I do this?’ you know, and I just decided, okay, I devised a method, you know, where I had to, because you can’t go on the floor, you know, if it’s carpeted. So the only way was to line the toilet paper to cover the seat, to line it there and you can then, I mean on there you can get your stick ready, dip it, dip it and that’s it. Then wrap it up and let it go in the toilet. But how many of us is going to think about that? And of course, asking them to wrap it up, because I had to get gloves to put on, so that, you know, and when I had finished, I wrapped it up and disposed of it.” (P33, African, male, 60 years, completed screening, SD 0).*

Participants who were unable to complete the FOBt independently, for instance, due to visual impairment, reported they would require the assistance of a significant other to help complete the test.

*“And concerning the collection, I think if I didn’t get my sister, I could not have done it... Well, because of my situations – not seeing properly, you know, couldn’t do it, without her help.” (P38, Black Other, female, 68 years, completed screening, SD 1).*

Another aspect related to the completion of the FOBt for all participants was the need to ensure that it could be scheduled around participants’ regular daily work or leisure activities, where the majority preferred to complete the test in the morning.

*“No, I think it’s best in the morning, not during the day, because during the day I go to luncheon clubs and things like that. And I think it’s best to do it first thing in the morning. And then it don’t break up the routine.” (P22, White British, male, 66 years, completed screening, SD 2).*

*“Well, I found that it’s going to be one day, once a day that I go to the loo. Therefore I knew when I started, I’ve got to finish, because I go as early as 7. Never miss, you know. Any day I don’t go, I don’t go out. But my system is such that between 6 and 7 in the morning, my system moves. So I know I’ve got to do it, that’s why I’ve planned it, when I’m going to do it over the weekend.” (P33, African, male, 60 years, completed screening, SD 0)*

## Skills

### *Procedural*

Participants of mainly White British origin, of varying SES, reported obstacles relating to the 'Skills' domain that could potentially hinder completion of the FOBt. These included physical problems such as arthritis in the hands and concerns about "bad knees" that could affect collection of the sample and transfer to the test kit.

*"I mean I've got a bit of arthritis myself. And if you have arthritis in your hands, physical manoeuvres are more difficult, and I think that's probably something that this review should bear in mind. Things like, for me, opening cartons of milk and of fruit juice, awkward buttons and things like that". (P14, White British, male, 62 years, declined screening, SD 0).*

*"It is awkward. I mean I've got bad knees anyway, so you would have to sort of start, and stop, and then when you're ending, then you've got to get another sample." (P7, White British, female, 68 years, declined screening, SD 2).*

### *Misunderstanding of instructions*

For participants who had either contemplated or attempted the FOBt, misunderstanding of the instructions for completion was an obstacle to screening participation, mainly for those of lower SES. However, those who were motivated to participate either consulted or planned to consult a healthcare professional (P13) or a partner (P16) for advice about how to complete the test. One individual (P23) did not complete the FOBt as he thought a large faecal sample was required and only realised that a smear was required during the interview.

*"You sent one to me, which I was going to do, because I didn't understand how to do it, I was trying to bring it to the nurse here, so that she know exactly what to do with it." (P13, African, female, 68 years, invited but not yet completed, SD 2)*

*“The first time when I was reading it, I never understand what it means. So I call her and said, they’ve sent this to me...she said you need to take the stick when you go to the toilet and then put it on here.” (P16, Caribbean, male, 67 years, started completion of FOBt but was told not to continue, SD 2)*

*“I didn’t read it properly, so I should have looked at this and saw this about a smear. I was thinking of an actual stool that, you know, that you had to put in a bag and send it off.” (P23, White British, male, 62 years, declined screening, SD 1).*

## **5.4 Discussion**

### **5.4.1 Overview of findings**

This study identified the beliefs about CRC screening of an ethnically and socio-economically diverse group of people from South East London. Overall, there were beliefs within all domains that either encouraged or discouraged participation in screening. For instance, in the ‘Beliefs about Consequences’ domain, some participants believed screening could prevent cancer whilst others believed screening was pointless as there is no cure for cancer. Moreover, many beliefs were shared across the different ethnic and SES groups such as the benefits of screening including reassurance that one did not have CRC (‘Beliefs about Consequences’). Participants of higher SES groups, regardless of ethnicity, appeared more confident about their ability to complete the FOBt. In contrast, low SES people, of any ethnic group, encountered more difficulties surrounding the comprehension of instructions for FOBt completion than those of higher SES.

As well as the similarities, there were also some notable differences between ethnic groups. Black African and Black Caribbean participants, of all SES levels, were more positive and accepting of screening than White British participants as evidenced by the ‘Beliefs about Consequences’, ‘Emotions’ and ‘Social role and identity’ domains. Moreover, Black African

and Black Caribbean participants of all SES backgrounds in particular endorsed a view that screening was important as it saved lives and prevented cancer. They also did not perceive any fear of screening, along with high SES White British participants. Furthermore, ethnic minority group participants felt a need to conform to the “rules” of the country they now lived in which encouraged them to take part in screening (‘Social role and identity’). Faith in God appeared to encourage participation in screening for Black African and Black Caribbean participants of varying faiths (‘Social role and identity’ domain). No other religious or cultural beliefs were reported to influence ethnic minority group participants’ decisions about participating in screening. Another encouraging factor for ethnic minority group participants was that screening was offered for free (‘Environmental context and resources’ domain).

Although many White British participants thought screening would prevent cancer, several White British participants, across all SES categories, were sceptical about the benefits of screening, had doubts that cancer could be prevented and were more averse to collection of the faecal sample. One participant of high SES (SD category 0, P5) drew on his knowledge of criticisms of research regarding prostate cancer screening as a reason for his doubts about CRC screening. White British participants in higher SES groups also reported concerns over potential false positive results and the overall accuracy of the FOBt, an issue not mentioned by any of the other ethnic groups.

In relation to ‘Knowledge’, many participants, regardless of ethnicity and SES, knew of someone with cancer, had experienced bowel related symptoms or had had a colonoscopy or had a previous cancer. Black African and Black Caribbean participants in particular, regardless of SES, were more knowledgeable about prostate cancer, which is known to have a higher incidence in these groups. Moreover, a consistent message from participants in ethnic minority groups was the lack of awareness and need to inform and promote screening through media campaigns and GP practices.



### **5.4.2 Discussion of findings**

The findings of this study suggest the factors that encouraged and discouraged participation in screening were similar to those cited in previous research as well as the literature examined in the systematic review in chapter four. Factors that appeared to encourage screening for Black African, Black Caribbean and White British participants in this study such as, knowing someone with CRC, previous experience of screening programmes, a perceived civic duty to participate in screening, encouragement from others and previous bowel problems were also endorsed by White British participants in a previous qualitative study (Chapple, Ziebland et al. 2008). Similarly, factors that appeared to discourage screening participation such as, handling a faecal sample, low perceived risk and misunderstanding instructions were also shared by White British participants (Chapple et al., 2008).

In terms of theoretical domains, the beliefs in each domain were also broadly similar in this study and in the systematic review. However, there were some exceptions that prevent the findings of the systematic review being generalised to the population in this study. Barriers reported in US based studies such as the lack of health insurance and cost of screening (O'Malley, Beaton et al. 2004, Choe, Tu et al. 2006), falling under the 'Environmental context and resources' domain, were not applicable due to difference in the organisation of screening in the UK. The finding in the systematic review that knowledge of screening was low in ethnic minority groups and those of low SES (Brouse, Basch et al. 2003, Khan 2010, Szczepura 2003 a&b, Schroy, Glick et al. 2008, (Techer, Weller et al., 2009, Weinrich, Weinrich et al. 1992) was replicated in this study but knowledge was also low in the White British group. This latter finding emphasises the importance of examining the views of majority ethnic group populations and minority groups, as well as socio-economic factors to avoid misattributing any differences in beliefs due to ethnic differences when they are in fact shared by particular ethnic or socio-economic groups. However, as demonstrated in the

systematic review in chapter four, ethnicity and socio-economic factors are rarely examined together in research about CRC screening.

A further area of difference between the findings of this study and the reviewed literature was that unlike people of South Asian origin (Szczepura, 2003a), fatalism was not a reported barrier to screening for Black African and Black Caribbean groups. In contrast, participants' faith in God on the whole, appeared to encourage participation in screening. One reason ethnic minority participants in the present study, irrespective of SES, were very positive about screening could be that the majority were highly educated. Several Black African and Black Caribbean participants either previously worked as nurses or had family members in the health professions which may have facilitated their understanding of screening. Moreover, the highly educated sample may reflect a potential bias in sampling where the ethnic minority participants who were accrued for this study were more educated than would be representative for the overall population of Lambeth and Southwark within the screening age range. However, this cannot be confirmed as the latest census results do not examine the education levels of specific age groups or ethnic groups.

### **5.4.3 Implications for South East London**

The findings of this study have some important implications for addressing low uptake of CRC in South East London. Firstly, the results from this study suggest that people may not be making informed choices about whether or not to participate in screening. Some participants held negative views about screening that appeared not to be based on good knowledge. For instance, one lady did not take part as she was put off by the faecal sample and another associated the FOBt with the supernatural occult. These participants could also be considered as making an uninformed choice not to participate in screening. Interestingly, both participants later said they would probably complete the FOBt upon their next invitation after knowing more about it through this study. Awareness of screening was

generally low in this cohort of participants but many of those who had been invited reported that they still took part, again suggesting a lack of informed choice. On the other hand, those who were unsure as to how they would complete the FOBt were less likely to participate in screening. Furthermore, participants wanted more information about screening in accessible, easy to understand formats. They also wanted screening to be more actively promoted by their GP practice and the NHS, as the lack of promotion at the time suggested to participants that screening was not important. These findings are consistent with a recent study by Waller, Macedo et al., (2012) who found a widespread preference amongst participants for a recommendation from the NHS to take part in CRC screening. However, alongside a preference for screening recommendation, participants also expressed a strong desire for detailed information regarding risks and benefits of screening. Taken together, the findings of the present study and the study by Waller et al., (2012) support the UK policy of providing information on the potential benefits and risks of screening tests in facilitating informed choices about screening (Department of Health 2011). Nevertheless, there is awareness that interpreting complex information in order to reach an informed choice may be more challenging for those from more socially deprived backgrounds, perhaps due to literacy barriers (Raffle 2001). Therefore, future work may benefit from focusing on effective ways of presenting information regarding cancer screening based on individual circumstances (Waller et al., 2012).

Using a comprehensive psychological theoretical framework helped elicit many beliefs that were salient to people's views about CRC screening. However, there are limitations of this approach as the TDF does not specify the relationships between the included domains and corresponding constructs (Francis et al., 2009). Moreover, although a range of beliefs have been identified; the qualitative nature of this study does not allow us to distinguish which beliefs were more or less salient than others in determining people's views about CRC screening and subsequent participation. For this, a quantitative design is required to identify

which beliefs most strongly predict people's intentions for screening, and how these relate to actual screening behaviour. This will be the objective of the next chapter.

#### **5.4.4 Strengths and limitations**

Strengths of this study included using a theory based interview schedule that facilitated the systematic identification of beliefs that encouraged and discouraged screening participation for people in South East London. The comprehensive coverage of the TDF allowed the identification of factors that are not usually included in theories of health behaviour, such as participants' perceived civic duty to participate in screening. A further strength was the exploration of ethnic and socio-economic variation; as demonstrated in the previous chapter, many previous studies have failed to consider both ethnicity and SES factors in relation to beliefs about CRC screening.

Some potential limitations of this study also warrant attention. Firstly, this study focused on a sample of participants who were recruited in GP practice waiting rooms. Although the GP setting allowed wide access to the local populations of Lambeth and Southwark, this may have led to biases in sampling by accruing participants who more motivated about their health and engaged with health services. It may be that participants who are already 'patients' may have different attitudes, motivations and beliefs about screening than those who do not visit their GP often. As existing 'help-seekers', they may be more positive about screening than those who do not engage with health services often. Furthermore, all practices were identified through academic GP colleagues and had been involved in previous research projects. It may be likely that participants were familiar with taking part in research and thus, more keen to contribute to this study as very few of the people approached to take part in this study refused.

#### **5.4.5 Reflexive section**

This section provides a reflexive account of the experience of conducting the interviews. A key issue was the general lack of awareness of colorectal cancer and the screening programme among participants. As a researcher, I found myself managing two roles during interviews; on one hand my role as a researcher and on the other, as an information source for participants. Participants tended to ask many questions about the causes of colorectal cancer, sensitivity of the FOBt, and sought clarification of FOBt completion instructions. In these instances, having a sample FOBt kit on hand to show participants who were unaware of the screening programme was very helpful in improving understanding of what screening involved and also allowed participants to reflect on otherwise hypothetical interview questions. However, this raises an issue on the fidelity of the findings as participants' views may have altered following receipt of this information and clarification of misunderstandings.

Quite a few participants thought I was a representative from the screening programme which may have contributed to power dynamics during interviews if I was perceived to have been promoting screening completion. Indeed many participants thought they were also consenting to take part in the screening programme when consenting to take part in the study, whilst a few expressed concerns I would ask them to complete screening and others apologised for not doing so. A further issue was that many participants reported not being invited for screening although they were within the age range of the screening programme. However, as interviews progressed, there were indications that perhaps these participants had some previous experience of awareness of the screening programme that they did not explicitly disclose. Such sensitivities made me mindful of ensuring a neutral stance to the screening programme so participants would be at ease at expressing their views, positive or negative. A related issue was the possibility that taking part in this research may have influenced participants' subsequent screening decisions. Where the issue was difficulty

understanding the instructions on completion, participants reported they would go home and start the FOBt as they felt confident they would now be able to complete it correctly. Of equal pertinence was the potential effect on participants who had not yet been invited for screening, where taking part in this research may have encouraged or deterred those who were naive to screening. However, as this was a cross-sectional study, participants' subsequent uptake of screening could not be determined.

Overall, the process of engaging and building rapport with participants from various backgrounds and exploring their responses about colorectal cancer screening was a rewarding experience. The challenge of negotiating a place for my research within GP practice administrative teams who had no real incentive, and at times interest, to help with recruitment made me appreciate just how integral building professional networks with different professional groups is to successful fieldwork.

#### **5.4.6 Conclusion**

In summary, using a comprehensive theory based interview schedule elicited a broad range of beliefs about CRC screening. Furthermore, this is the first study to provide detailed information on the views about Black African and Black Caribbean participants about screening. The findings revealed many similarities between the different ethnic and SES groups across the TDF domains including 'Knowledge' and 'Beliefs about Consequences' as well as some interesting areas of difference in terms of 'Emotions' and 'Social role and identity'. The aim of this study was to examine the pattern of beliefs about CRC screening in South East London. The next step is to use these findings to construct a questionnaire and examine the factors that predict both intentions and uptake of screening and this is the objective of the next chapter.

## Chapter Six

### **Predicting intentions and uptake of CRC screening uptake in South East London; A Prospective Questionnaire Survey**

#### **Abstract**

**Aims:** To examine the influence of SES and ethnicity on screening uptake in South East London and to explore the psychological factors underpinning screening uptake and any demographic variations in uptake. In order to achieve this, the following hypotheses will be tested:

1. Uptake of CRC screening in South East London is predicted by SES, with people with lower SES being less likely to be screened
2. Uptake of CRC screening in South East London is predicted by ethnicity with people from ethnic minority groups being less likely to be screened
3. People of different levels of SES will have different beliefs about CRC screening
4. People of different ethnic backgrounds will have different beliefs about CRC screening
5. Psychological beliefs will mediate the impact of demographic factors on screening intentions and uptake
6. People of lower SES will be less likely to make an informed choice about screening

**Design:** Prospective questionnaire survey

**Methods:** Using the qualitative data, the most prominent beliefs in each domain of the TDF were developed into questionnaire items. Individuals from SE London who were due to be invited for CRC screening were invited to participate in the questionnaire survey. In a prospective design, consenting individuals (n=507) completed questionnaires through telephone interviews two months before being invited for CRC screening. Ethnic groups included in the analysis were Black African (n=29), Black Caribbean (n=40), White British (n=354) and White Other (n=55). Participation in screening was subsequently recorded by the London Screening Hub.

**Results:** Logistic regression indicated that ethnicity, intentions for screening and behavioural regulation predicted the uptake of screening. Furthermore, multiple regression

indicated that ethnicity, *beliefs about capabilities*, *beliefs about consequences*, *knowledge*, *'environmental context and resources'* as well as the perceived approval of screening by significant others predicted screening intentions. SES did not appear to be related to screening intentions or behaviour but was associated with informed choice where more deprived groups were less likely to make an informed choice about screening participation. In addition, psychological factors were found to partially mediate the effect of demographic differences in screening intentions and uptake.

**Conclusion:** As expected, there were ethnic differences in intentions for, and the uptake of, screening. However, the finding that SES factors were not related to screening intentions or uptake requires further replication due to this study accruing fewer numbers of participants from more socially deprived backgrounds. The findings of this study can help inform the design of interventions to influence screening uptake.



## 6.1 Introduction

The findings of the qualitative study in the previous chapter highlighted a number of recurring beliefs that appeared to encourage or discourage participation in CRC screening. Due to the exploratory nature of qualitative research, it is not clear from the findings in the previous chapter as to how beliefs across different domains may be linked and which beliefs go on to predict screening behaviour. The beliefs identified in the qualitative study were thus translated into questionnaire items with the aim of quantitatively examining the factors that determined people's intentions of screening as well as screening uptake. The present study will address all of the research questions that were outlined in chapter one. Firstly, this study will indicate whether there are any significant differences in the views of the ethnic and socio-economic groups of South East London about CRC screening. Secondly, the study will further allude to the role of ethnicity, socio-economic, psychological factors and informed choice in determining the low rates of screening uptake reported in South East London. Finally, this study will also examine whether the relationship between demographic factors and uptake is mediated by psychological factors. The findings of this study will enable the development of appropriate intervention strategies to influence screening participation. Overall, this prospective questionnaire survey is novel in its examination of the role of ethnicity and SES alongside psychological factors in relation to uptake of CRC screening.

The specific objectives of this study were:

1. To identify the demographic and psychological predictors of screening intentions
2. To identify the demographic and psychological predictors of screening uptake
3. Examine the patterning of psychological beliefs by ethnicity and SES
4. Conduct mediation analysis to identify the causal pathways between any significant relationships between the demographic and psychological variables and screening intentions and uptake

5. Evaluate the extent of informed choice took place and examine the possible predictors

## **6.2 Method**

### **6.2.1 Participants**

People living in Lambeth and Southwark, aged between 60 and 69 years, which was the age range of the CRC screening programme at the time of this study, were invited to take part in this study. The only eligibility criterion was that potential participants would be receiving an invitation for screening two months after being invited for the study. Data collection took place two months before participants received their screening invitations, as stipulated by the NHS Bowel Cancer Screening Research Committee (NHS BCSRC), that oversees research associated with the CRC screening programme.

The experience of opportunistic recruitment of participants for the qualitative study, where success relied upon the willingness of GP practice staff to identify potential participants, highlighted the need for a more systematic and inclusive recruitment strategy in order to increase the chances of accruing a representative sample. Therefore, contact was made with the Screening Hub at St. Marks' Hospital, which co-ordinates the screening for the whole of London, to aid participant recruitment in this study. Potential participants were randomly identified from an internal database by staff at the Screening Hub so the author did not have any access to any personally identifiable information.

### **6.2.2 Design**

A prospective questionnaire survey was conducted where psychological beliefs were measured through a single telephone interview, two months prior to participants being invited for screening. Participants were unaware that they would be invited for screening in

two months time. With participants' consent, uptake and non-uptake information was subsequently gathered from the Screening Hub. It is recognised that asking individuals questions about a behaviour may increase the likelihood that they later perform the behaviour; a phenomenon known as the question-behaviour effect (QBE), measurement reactivity or mere measurement (Conner, Godin et al. 2011). The two month time frame was therefore agreed as a distant enough time frame with the BCSRC to not have an adverse impact upon the screening programme and still be short enough to reduce the chances of reported beliefs having changed, which can be a reason for poor prediction of behaviour (Ajzen and Timko (1986).

Telephone interviews were chosen as the data collection method in order to minimise potential literacy barriers that may exist in the local population who were living in areas of high social deprivation. Moreover, during the qualitative interviews, several participants reported difficulties with reading and understanding the instructions to complete the FOBt as a potential barrier for participation in screening. Thus, with these issues in mind that participation in this study was made as burden-less, accessible and convenient for participants as possible.

### **6.2.3 Procedure**

Prior to data collection, NHS ethical approval was received as an extension to the qualitative study (REC ref: 10/H0701/2). In addition, approval had to be sought from the BCSRC in order to include people who were going to be invited for screening. Internal data sharing agreements between the author and the Screening Hub were also completed once it was established that approval from the National Information Governance Board (NIGB) for Health and Social Care, was not required. All study approvals can be found in appendix 6.1.

Potentially eligible participants were sent a study invitation letter (appendix 6.2), information sheet (appendix 6.3), consent form (appendix 6.4) and a reply slip (appendix 6.5). Those who were interested in taking part were asked to sign the accompanying consent form and return it together with a reply-slip with their telephone number and convenient time to call, in the freepost return envelope that was provided. Completed reply slips were delivered directly to the researcher and any undeliverable post was delivered back to the Screening Hub. Each individual was assigned a unique reference number that was printed on their consent form and reply slip in order to facilitate the anonymised feedback with the Screening Hub on responders and non-responders, and later on screening uptake.

In line with recommendations for good practice in survey research (McColl, Jacoby et al. 2001, Nakash, Hutton et al. 2006) study invitees were sent a reminder letter (appendix 6.6) two weeks after the initial invitation letter if a response had not been received within this time. Those who had indicated on the reply-slip that they did not wish to participate were not sent a reminder letter and no further contact was made with those individuals.

The telephone interviews were mostly performed in a private room at Kings College London by the author. A team of five student research assistants (RAs) was later appointed to help carry out the interviews in order to complete data collection within the two month time frame. RAs were given a full induction and training, and practiced interviewing prior to conducting interviews with participants. The first few 'live' interviews by each RA were conducted on speaker phone so they could be monitored by the author. None of the interviews were audio-recorded as responses were noted directly on a paper copy of the questionnaire. All questionnaires were anonymised using the unique identifier created by the Screening Hub and securely stored in a locked cabinet. Telephone interviews were arranged entirely according to participants' convenience and took up to 30 minutes to complete.

Research has shown small incentives have been helpful in increasing response rates and decreasing the number of non-responders in questionnaire surveys (Oppenheim 2000); (Brealey, Atwell et al. 2007). After consulting colleagues who had carried out survey research locally, participants in this study were offered a small token of thanks in way of a £20 gift token in recognition of their time given for the study, for which funding was available. The amount offered was not considered as sufficiently large enough to have a coercive influence on whether individuals consented to participate in the study (Brealey et al., 2007). However, there was hope that by providing a token in recognition of the time participants had to give to take part in the study, participation from those otherwise less inclined to engage in research and perhaps screening would be encouraged. Participants were sent the gift vouchers along with a letter of thanks (appendix 6.7)

## **6.2.4 Measures**

### **6.2.4i Psychological beliefs**

The questionnaire was developed using the results of the qualitative interview study reported in chapter five. The full questionnaire is available in appendix 6.8. Recommendations for constructing a TPB questionnaire set out by (Ajzen 2002) were used as a guide for identifying the most common salient beliefs of the target population: residents of South East London. Salient beliefs are the beliefs that first come to mind when people are asked open-ended questions about any given behaviour (Sutton, French et al. 2003). As outlined in chapter three, social cognitive theories propose that individuals' salient beliefs are also the determinants of behaviour, operating through various theoretical constructs such as intentions and attitudes. Where relevant, questions incorporated the behaviour of interest; completion of the FOBt. In order to ensure the questionnaire was comprehensible and to maintain consistency with language used by the NHS and various cancer charities (e.g. Cancer Research UK, Macmillan), CRC was referred to as 'bowel cancer' in all study materials, including the questionnaire.

According to Ajzen (2002), the next step is to use the most commonly elicited beliefs as the basis for a quantitative examination of the determinants of behaviour. As the results of the qualitative study were mapped onto the domains of the TDF, the same domains were used as the basis for the questionnaire. In order to determine which beliefs were salient, the matrices generated during framework analysis of the qualitative data were re-examined for each domain of the TDF. However, being mindful of ensuring minimal burden to participants, a challenging task was deciding on the number of beliefs to include for each theoretical domain as some domains such as 'Beliefs about Consequences' contained several salient beliefs whereas, others such as 'Skills' contained relatively few beliefs. Ajzen and Fishbein (1980), as cited in Sutton, French et al., (2003), suggested including beliefs that were held by 20% of the sample. A cautionary step was to ensure that beliefs that were not salient were not included in the questionnaire as there is a risk that presenting non-salient beliefs may lead to a change in participants' attitudes (Sutton et al., 2003). An initial list of salient beliefs was compiled and cross checks were made to determine the frequency of endorsed beliefs across the different ethnic groups. Beliefs that were endorsed by 20% of all ethnic groups were included. Question wordings were written and all items were phrased to refer specifically to completion of the FOBt when participants were (next) invited for screening.

The final questionnaire included 47 items across the twelve domains of the original version of the TDF (Michie et al., 2005). Subject to satisfactory internal reliability of items within each domain, the average score across all items was used to create a scale for each domain. All items were scored on a five point Likert scale with the response options for most items ranging from 1 strongly disagree to 5 strongly agree. The scale for the item regarding perceived risk of CRC was worded according to convention as in previous studies (*"Compared to other people my age, I think my risk of getting bowel cancer is"*) where response options were: 1 much lower, 2 lower, 3 about the same, 4 higher and 5 much higher (Weinstein 1987, Wardle, Williamson et al. 2003, Robb, Power et al. 2008).

In addition to the TDF, four items, adapted from Smith et al., (2010), measuring participants' conceptual knowledge of CRC screening were also included. Scale responses were adapted to refer to the UK incidence of CRC as Smith et al.'s study was based on Australian data. The conceptual knowledge scale was included to determine whether participants in this study had made an informed choice to take part in screening or not (see below).

#### **6.2.4ii Informed choice**

The measure of informed choice used in this study was based on the conceptualisation by Marteau et al., (2001) that characterises an informed choice as “one that is based on relevant knowledge, consistent with the decision-maker's values and behaviourally implemented” (Marteau et al., 2001, p.4). Thus, there are three elements to measuring informed choice that were initially assessed individually and then later combined: knowledge, values or attitudes and screening behaviour. Knowledge was assessed through four items, adapted from Smith et al., (2010), that examined participants' knowledge about the outcomes of screening in terms of likelihood of death from CRC without symptoms for a person aged over 60 years, likelihood of death from CRC if one completed the FOBt, the meaning of an ‘abnormal’ result and whether screening would detect every case of CRC. Attitudes were assessed by averaging the responses from two items within the ‘beliefs about consequences’ domain that closely resembled the measurement of attitudes by Marteau et al., (2001): “for me, taking part in CRC screening would be beneficial” and “for me, taking part in CRC screening would be important”. As recommended by Marteau et al., (2001), a pragmatic approach, by way of a median split, was taken in order to distinguish participants with ‘adequate’ and ‘inadequate’ levels of knowledge (median=2) and those who held positive and negative attitudes (median= 4.5). Therefore, participants scoring above the median on the revised knowledge and attitude scales were deemed as having ‘adequate’ knowledge and a positive attitude and those scoring below the median for were deemed as having ‘inadequate’

knowledge and a negative attitude, respectively. Screening behaviour, assessed by the Screening Hub, was dichotomised as either ‘completed the FOBt’ or ‘did not return a completed FOBt’. Participants were considered to have made an informed choice if they a) had a positive attitude towards screening, adequate knowledge and completed the FOBt, or b) had a negative attitude towards screening, adequate knowledge and did not return a completed FOBt. Participants who had inadequate levels of knowledge or if their attitudes were not consistent with their actual screening behaviour (e.g. completed the FOBt despite a negative attitude) were considered to have made an uninformed choice about screening.

#### **6.2.4iii Socio-demographic factors**

All socio-demographic factors were measured by self-report including participants’ age, ethnicity, SES, gender, previous uptake of CRC screening and family history of CRC. Ethnicity was measured according to categories of the 2001 census. With regards to SES, as outlined in chapter two, multiple measures including Social Deprivation (comprising of housing tenure, car ownership and level of education) and participants’ post code (to derive IMD quintile) were collected. Participants’ full address was also collected in order to dispatch the gift vouchers.

#### **6.2.4v Measuring behaviour**

With participants’ consent, information regarding their subsequent response or non-response to screening was extracted by staff at the Screening Hub. For the purpose of this study, uptake was defined as successful completion and return of a FOBt kit (yes/no). This was used as the objective measure of behaviour in order to avoid the potential biases surrounding self-reported screening uptake. Once again, no other personal information about participants or the details of their screening results were accessed for this purpose. Participants who did not consent to the researcher receiving information about uptake did not have this data retrieved or shared with the author. According to the Screening Hub protocol, people invited for



screening have up to 13 weeks to complete and return their FOBt following the initial screening invitation. Thus, participants in this study who did not return a FOBt within the 13 week period were classed as non-responders.

### **6.2.5 Piloting of questionnaire**

Extensive piloting of the questionnaire was undertaken to ensure it was easy to understand and acceptable to the target population. Feedback via a feedback form (appendix 6.9) was gathered from several departmental colleagues, an academic GP and members of the project steering group who were asked to evaluate the questionnaire on the following criteria:

1. Whether there were any questions that did not make sense or were difficult to understand
2. If any question sounded odd or was confusing
3. If any question was difficult to answer
4. Whether they thought any question could have more than one meaning
5. If there was any question that should be removed from the questionnaire

Following suggested amendments to some question wordings, the final version of the questionnaire was mailed to five participants who took part in the qualitative study and had agreed to act as user representatives. Only one reply was received from a male Black African participant who did not highlight any issues with the questionnaire.

### **6.2.6 Sample size**

Following advice from the departmental statistician, the target sample size was 500 participants. With this number, it would be possible to detect an odds ratio of 2 for the effect of ethnic minority group membership on screening uptake. This was expected to yield 84% power at the 5% significance level for two-sided tests where ethnicity was disproportionately distributed in the whole sample with approximately 80% of the sample

estimated to be White British and 20% belonging to ethnic minority groups. Recruitment could not be targeted towards specific ethnic groups as ethnicity information was not available in the Screening Hub records which themselves are derived from NHS primary care records.

To account for a response rate of 20% reported in a previous survey research (McColl et al., 2001, Sahlqvist, Song et al. 2011), 2500 people were initially invited to take part in this study. Recruitment was designed to occur in across three monthly blocks where 840 people were invited in July 2011, 840 people were invited in August 2011 and 820 people were invited in September. As expected participant numbers were not accrued within this time frame, an extra 840 people were invited to take part in the study in October 2011. Recruitment was selective to the extent that half of the people invited for the study each month resided in Lambeth and half resided in Southwark.

### **6.2.7 Data analysis**

Univariate, multivariate and mediation statistical analyses were conducted using PASW v. 20. In addition, the mediation analysis was undertaken using the PROCESS and MEDIANTE macros for SPSS (Hayes 2012).

Multiple regression analysis was used to examine the psychological predictors of screening intentions. However, in order to examine the demographic predictors of screening intentions, factorial ANOVAs were conducted as the predictor variables (ethnicity and the various SES indicators) were categorical in nature and the outcome (intention) was measured on a continuous scale. A series of binary logistic regressions were undertaken to determine the influence of ethnicity and SES as well as psychological factors on screening uptake, which was a dichotomous outcome variable. Analyses were run separately for ethnicity and for each SES indicator (education, social deprivation and IMD quintile). The effects of ethnicity

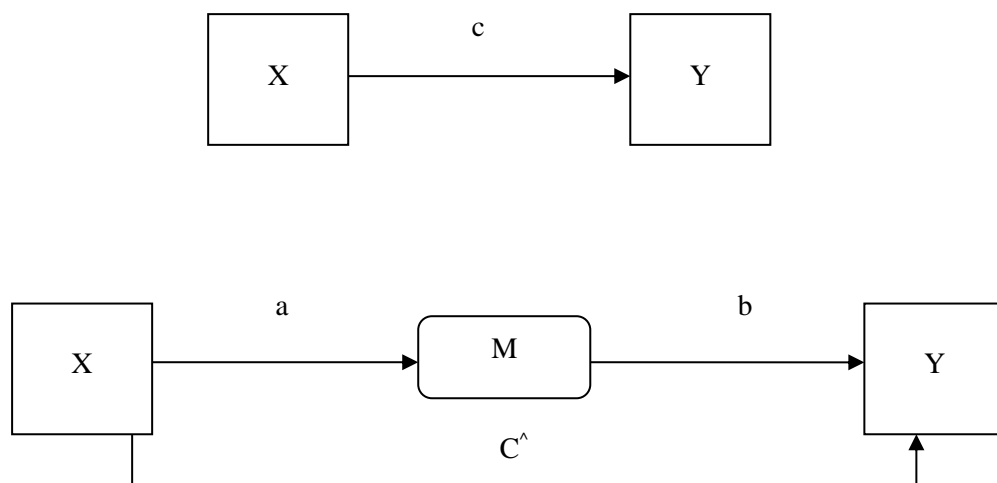
whilst controlling for SES on screening behaviour were examined when SES factors were also found to be significant predictors of screening uptake. In addition, for the psychological factors, analysis was run once including intentions and once without to examine any other significant predictors of behaviour apart from intentions.

A series of one-way ANOVAs were conducted to examine whether psychological beliefs varied by ethnicity and each indicator of SES. Sidak corrections were applied to examine pairwise comparisons and minimise the occurrence of type 1 error and increase power in light of the number of comparisons that were required. In order to examine variation in psychological beliefs by both ethnicity and SES, factorial ANOVAs were conducted for each domain and individual item, resulting in 26 separate tests (10 domains and 16 individual items). Due to the relatively large number of tests, this latter analysis included ethnicity and only SD as the indicator of SES. SD incorporates one of the other measure of SES, level of education, and is preferred to IMD quintile as it represents an individual index of deprivation as opposed to a more general area based deprivation index.

In relation to informed choice, logistic regression analyses were undertaken to examine the demographic predictors. The relationship between any significant demographic predictors and informed choice was subsequently examined in mediation analysis that included psychological factors as potential mediators.

Mediation analysis was undertaken to examine the role of psychological factors as possible mediators of the relationship between demographics (ethnicity and SES) and screening intentions and uptake. The goal of mediation analysis is to determine the extent to which a proposed causal variable *X* (such as ethnicity), influences an outcome *Y* (such as screening uptake) through one or more intervening or mediator variables (Hayes, 2012). PROCESS (Hayes, 2012), is a computational procedure devised to undertake mediation analysis. Its advantages include having greater power than Baron and Kenny's (1986) causal steps

approach and that, unlike the Sobel test, it does not assume the sampling distribution of the indirect effect is normal (Hayes, 2012). Mediation analysis provides omnibus tests for direct, indirect and total effects for the proposed causal variable  $X$  on outcome variable  $Y$ . A path diagram showing simple and multiple mediation models is presented below in figure 6.0. In the top part of the figure,  $c$  represents the total effect of causal variable  $X$  on outcome variable  $Y$  and in the bottom part,  $C^\wedge$  represents the direct effect of  $X$  on  $Y$  after controlling for the proposed mediator (Rucker, Preacher et al. 2011). The effect of the causal variable/independent variable  $X$  on the mediator is represented by  $a$ , and the effect of the mediator on the outcome variable  $Y$  is represented by  $b$ . Finally, the indirect effect of  $X$  on  $Y$  is the product of  $a$  multiplied by  $b$  (Rucker, Preacher et al. 2011).



**Figure 6.0:** A path diagram representing a simple mediation model

Mediation analysis was only conducted on demographic factors that were significant predictors of screening intentions and uptake. The MEDIANTE macro (Hayes, 2012) was used for mediation analysis of demographics and intentions as the former were categorical in nature and the outcome (intention) was continuous. Dummy codes were thus created for each ethnic group, with White British participants being the reference group across all comparisons. Dummy codes were not required for SES indicators as they could be deemed

as being ordinal as well as categorical, where higher scores reflected higher levels of SES. The possible psychological mediators were also included on the basis that they were significant predictors of screening intentions and behaviour in earlier multiple and logistic regression analyses. In order to provide robust results that would mitigate any violation of parametric assumptions of the data, bootstrapping was allowed in the mediation analysis so that the analysis could be rerun with resamples taken from the overall sample. In this case, the result was bootstrapped with 1000 resamples and the mean effect for those resamples was calculated. The final mediation analysis concerned the relationship between informed choice and the various SES indicators (level of education, social deprivation and IMD quintile).

## **6.3 Results**

### **6.3i Results overview**

*6.3.1 Questionnaire reliability*

*6.3.2 Participant demographics*

*6.3.3 Demographic predictors of screening intentions*

*6.3.4 Psychological predictors of screening intentions*

*6.3.5 Demographic predictors of screening uptake*

*6.3.6 Psychological predictors of screening uptake*

*6.3.7 Variation in psychological beliefs by Ethnicity and SES*

*6.3.8 Mediators of screening intentions and uptake*

*6.3.9 Demographic predictors of informed choice*

*6.3.10 Mediators of informed choice*

### 6.3.1 Questionnaire reliability

The internal reliability of each subscale of the TDF in the questionnaire was assessed. The *a priori* level of internal reliability acceptability was 0.7. Cronbach's  $\alpha$  values for several subscales were found to be very low, denoting low reliability: Beliefs about Capabilities (3 items; Cronbach's  $\alpha=.57$ ), Beliefs about Consequences (11 items; Cronbach's  $\alpha=.42$ ), Emotions (6 items; Cronbach's  $\alpha=.49$ ), Environmental Context and Resources (4 items; Cronbach's  $\alpha=.12$ ) Knowledge (2 items; Cronbach's  $\alpha=.66$ ), Memory, attention and decision (2 items; Cronbach's  $\alpha=.40$ ), Motivation and goals (3 items; Cronbach's  $\alpha=.56$ ), Nature of Behaviour (4 items; Cronbach's  $\alpha=.40$ ), Skills (2 items; Cronbach's  $\alpha=.18$ ), Social Influence (4 items; Cronbach's  $\alpha=.01$ ), Social role and identity (3 items; Cronbach's  $\alpha=.24$ ). In its original form in the questionnaire, the Behavioural Regulation domain comprised of a single item.

The low internal reliability of questionnaire sub-scales suggested that in the originally intended theoretical domains, the questionnaire items were not as closely related as anticipated. Thus, any subsequent analysis using these sub-scales would be flawed based on unreliable measures. Exploratory factor analysis via principle axis factoring with oblique rotation was therefore conducted on all questionnaire items to examine the underlying nature of the structure of domains within the questionnaire data. As recommended by Tabachnick and Fidell (2007), the best way to decide whether to run an oblique or orthogonal rotation is to first run an oblique rotation and examine the correlations between the factors. As multiple factors were correlated above 0.32 (Tabachnick and Fidel, 2007) this indicated that there was some overlap in the factors and thus an oblique rotation was warranted.

The results indicated significant refinement of the questionnaire where many domains were restructured; some were renamed whilst others were removed entirely. The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the new analysis, KMO=.86 (Field 2009).

Table 6.0 overleaf, displays the results of the factor analysis with the structure of the new factors and their corresponding reliability scores. The figures in the table represent the factor loadings across the questionnaire items. The factor loading cut-off for inclusion of items in a factor was 0.3. The eight factor final model explained 41.68% of the variance and was preferred due to the theoretical fit of the factors, all factors having eigen values greater than 1 and the 'levelling off' of the scree plot after eight factors. Two factors were renamed to reflect the beliefs that comprised each domain. The 'social role and identity' domain was thus renamed 'social and religious influence', and 'environmental, context and resources' was renamed 'practical barriers'. Reliability analysis was repeated for the revised questionnaire scales where the majority of domains had satisfactory levels of internal consistency. However, there were three domains that still had inadequate internal consistency (social and religious influence;  $\alpha=.44$ , memory and behavioural regulation;  $\alpha=.40$ ). In addition to eight factors, there were sixteen individual items that did not fit into any one theoretical domain and as such, were examined individually in subsequent analyses. These items are listed at the end of Table 6.0. The intention and conceptual knowledge scales were not included in the exploratory factor analysis as the intention scale had a very high internal reliability ( $\alpha=.95$ ) and conceptual knowledge was initially only included for the purpose of measuring informed choice ( $\alpha=.70$ )

**Table 6.0:** Refined questionnaire structure as a result of exploratory factor analysis (EFA)

Questionnaire item	Beliefs about capabilities Cronbach's $\alpha=.77$	Emotions Cronbach's $\alpha=.67$	Knowledge Cronbach's $\alpha=.61$	Practical barriers Cronbach's $\alpha=.63$	Factor	Beliefs about consequences Cronbach's $\alpha=.82$	Social & religious influence Cronbach's $\alpha=.44$	Memory Cronbach's $\alpha=.40$	Behavioural regulation Cronbach's $\alpha=.55$
It would be easy for me to read and understand the instructions about how to do the test	.671								.212
CRC screening using the FOBt is organised in a way which makes it easy for me to take part	.534					-.234			
I am confident I could complete the FOB test	.486	-.201				-.245			
I could easily fit doing the FOB test into my daily routine	.340					-.219			
I would feel embarrassed doing the FOB test		.592							
It might be difficult to collect the sample without making a mess.		.523							
I'd be concerned about how to store the FOBt securely while I'm collecting samples across the 3 days		.469							
I would be worried about putting the completed FOBt kit in the post		.411		.221					
I would be scared of doing the FOB test in case cancer is found		.363							
Thinking about bowel cancer makes me feel scared		.337							
I feel I don't know very much about bowel cancer			-.751						



Questionnaire item	Beliefs about capabilities Cronbach's $\alpha$ = .77	Emotions Cronbach's $\alpha$ = .67	Knowledge Cronbach's $\alpha$ = .61	Practical barriers Cronbach's $\alpha$ = .63	Factor	Beliefs about consequences Cronbach's $\alpha$ = .82	Social & religious influence Cronbach's $\alpha$ = .44	Memory Cronbach's $\alpha$ = .40	Behavioural regulation Cronbach's $\alpha$ = .55
I feel I don't know very much about bowel cancer			-.701						
There is no cure for bowel cancer			-.342						
I would not be able to complete the FOB test as it is disgusting		.213		.705					
There are too many issues in my life for me to complete bowel cancer screening at the moment				.593					
It would be difficult for me to complete the FOB test because I have a mobility problem, such as arthritis				.326					
For me, taking part in bowel cancer screening would be important					-.817				
For me, taking part in bowel cancer screening would be beneficial					-.751				
Screening is important as the NHS devotes resources to it					-.560				
It is important to me to know whether I have bowel cancer or not					-.534				
Doing the FOB test could save my life					-.529	.317			
My taking part in bowel cancer screening will benefit the NHS					-.449				
My religious or spiritual beliefs make me want to help myself stay healthy.							.481		

Questionnaire item	Beliefs about capabilities Cronbach's $\alpha$ =.77	Emotions Cronbach's $\alpha$ =.67	Knowledge Cronbach's $\alpha$ =.61	Practical barriers Cronbach's $\alpha$ =.63	Factor Beliefs about consequences Cronbach's $\alpha$ =.82	Social & religious influence Cronbach's $\alpha$ =.44	Memory Cronbach's $\alpha$ =.40	Behavioural regulation Cronbach's $\alpha$ =.55
I would like to know if my GP thinks me doing the FOBt is a good idea						.426		
I'd be more likely to complete bowel cancer screening if I knew lots of other people had also done so.		.234				.403		
I might have difficulty remembering to complete the test							.592	
In order to complete the FOB test, I would need put the test kit somewhere where seeing it will remind me to do it						.240	.483	
I would need help from another person to complete the FOBt test					.210			-.536
I could plan when and where I'll complete the FOB test kit								.459

The sixteen individual items that did not fit into any of the domains following the EFA were:

Perceived risk, Screening would be pleasant, Anticipated regret, Early detection leads to successful treatment, Would need to complete FOBt at home, Relief at normal result, bowel cancer is fatal, Important to keep healthy, Would need regular bowel function to complete FOBt, bowel cancer is a hidden disease, Religious beliefs would not impact if did screening, Important to look after self for family, FOBt would better than sample in a pot, Would be inappropriate to discuss bowel cancer screening with others, People close to me would approve of me completing the FOBt and Religious beliefs say no to bowel cancer screening.

### **6.3.2i Participants' demographic characteristics**

A total of 3340 people were invited to take part in this study of whom 849 people returned a reply slip, yielding an overall response rate of 25.4%. Of those who returned a reply slip, 608 people (71.6 %) indicated they wanted to take part in the study and the remainder indicated no interest (n= 241). A total of 507 participants (15.18% of the total people invited) were interviewed, yielding an interview rate of 83.38% of those who responded. Interviews could not be completed with 101 consenting people as they were either uncontactable or a convenient time for interview could not be arranged.

The demographic characteristics of participants are shown in Table 6.1, overleaf. Although roughly equal numbers of residents from Lambeth and Southwark were invited to take part in this study, 264 participants were from Lambeth and 243 were from Southwark. Furthermore, slightly more women than men participated in this study. However, as participants were randomly identified by the screening hub, there was no way of checking whether more women than men had been invited to take part in the study. Male and female participants were similar in terms of their ages. In terms of ethnicity, the majority of the sample (69.8%) described themselves as “White British”, 10.8% of participants originating from countries including Australia and Ireland described themselves as “White Other”, 7.9% described themselves as “Black Caribbean” and 5.7% described themselves as “Black African”. Due to the small numbers of participants from other ethnic groups, such as people of Chinese, Filipino, South American or South Asian origin, the analyses of the impact of ethnicity on screening beliefs and behaviour were restricted to include White British, White Other, Black African and Black Caribbean participants (n=478).

In relation to SES, when a composite measure including housing tenure, car ownership and educational qualification was used (Wardle et al., 1999), nearly half the participants (49.1%) were in the intermediate Social Deprivation (SD) category, 42.2% were in the least SD

category and 9.7% were in the highest SD category. Participants' SES profile was different when neighbourhood IMD quintiles were examined. The majority of participants (42.4%) resided in the most deprived 20% of areas in England compared to 3.7% of participants who resided in areas of low deprivation. As shown in table 6.1 below, there were relatively few participants in IMD quintiles four and five and so the two categories were collapsed to create a category that represented those who lived in the top 40% of the least deprived areas. With regards to level of education, over a third of participants (37.3%) were educated to degree level or higher, almost a third (27.8%) were educated to A level or equivalent and 11.6% were educated to G.C.S.E/O level or equivalent. 22.9% of participants did not hold any formal educational qualifications.

In terms of previous CRC screening, 43.4% of participants reported they had previously taken part in screening via the FOBt and 31.4% reported they had declined previous screening invitations. Approximately one quarter (25.2%) of participants reported they had never been invited to take part in CRC screening via the FOBt.

**Table 6.1:** *Demographic characteristics of participants*

		N	(%)
<b>Gender</b>	Men (mean age 62.27 years, S.D. 3.01)	232	(45.8)
	Women (mean age 62.53 years, S.D. 3.27)	275	(54.2)
<b>Ethnicity</b>	Black African	29	(5.7)
	Black Caribbean	40	(7.9)
	Black Other	6	(1.2)
	Chinese	1	(0.2)
	Filipino	2	(0.4)
	Middle East	2	(0.4)
	South Asian	8	(1.6)
	Other Asian	2	(0.4)
	Turkish	3	(0.6)
	White British	354	(69.8)
	White Other	55	(10.8)
	Prefer not to say	5	(1.0)

<b>Social deprivation – based on housing tenure, car ownership and educational qualification</b>	SD 0 Lowest deprivation	209 (41.2)
	SD 1 Intermediate deprivation	249 (49.1)
	SD 2 Highest deprivation	49 (9.7)
<b>Social deprivation – IMD quintile*</b>	5 (Least deprived)	3 (0.6)
	4	16 (3.2)
	3	74 (14.6)
	2	198 (39.1)
	1 (Most deprived)	215 (42.4)
	Missing	1 (0.2)
<b>Level of education*</b>	Undergraduate degree or higher	189 (37.3)
	A Level or similar	141 (27.8)
	G.C.S.E/O Level or similar	59 (11.6)
	No formal qualifications	116 (22.9)
	Missing	2 (0.4)
<b>Self reported previous screening status</b>	Completed	220 (43.4)
	Declined	159 (31.4)
	Not invited	128 (25.2)

\* denotes missing values where information was not provided

### 6.3.2ii Variation in SES indicators for members of different ethnic groups

Chi-square tests of independence indicated that significant differences existed between the SES characteristics of the four main ethnic groups that were included in the main analysis. Tables 6.2, 6.3 and 6.4 below, display the frequencies and percentages for each of the SES indicators by ethnic group.

**Table 6.2:** Ethnicity cross tab by Social Deprivation

<b>Ethnicity</b>	<b>Social Deprivation</b>		
	SD 0 Least deprived	SD 1 Intermediate deprived	SD 2 Most deprived
White British	167 (47.2%)	157 (44.4%)	30 (8.5%)
Black African	1 (3.4%)	25 (86.2%)	3 (10.3%)
Black Caribbean	6 (15%)	21 (52.5%)	13 (32.5%)
White Other	23 (41.8%)	30 (54.5%)	2 (3.6%)

There was a significant difference in the Social Deprivation (SD) category of the ethnic groups ( $\chi^2$  (6, N= 478)= 53.22,  $p<0.001$ ), For those in the lowest SD category, defined as those who held an educational qualification, owned their own home and owned a car, 47.2% of participants were White British, 41.8% were White Other participants, 3.4% were Black African participants and 15% were Black Caribbean participants. The majority of Black African, Black Caribbean and White Other participants were in the intermediate SD category, indicating that they held an educational qualification and either owned their own home or owned a car, compared to a smaller proportion of White British participants. Overall, except for Black Caribbean participants, proportions of the majority of ethnic groups were smaller for the highest SD category, characterised by lack of educational qualification and lack of home or car ownership.

**Table 6.3:** Ethnicity cross tab by IMD quintile

Ethnicity	IMD quintile			
	1 Most deprived 20%	2 20%	3 20%	4 Least deprived 40%
White British	130 (36.7%)	146 (41.2%)	60 (16.9%)	16 (4.5%)
Black African	19 (65.5%)	8 (27.6%)	2 (6.9%)	0
Black Caribbean	28 (70%)	11 (27.5%)	1 (2.5%)	0
White Other	28 (51.9%)	20 (37%)	5 (9.3%)	1 (1.9%)

Significant differences between ethnic groups were also found by neighbourhood deprivation measured using the IMD quintiles ( $\chi^2$  (12, N= 477)= 32.30,  $p=0.001$ ). Participants from White British and White Other ethnic groups were the only ones to reside in the 40% of least deprived areas albeit small proportions. The majority of Black African, Black Caribbean and White Other participants resided in the most deprived 20% of neighbourhoods, compared to a relatively smaller proportion of White British participants.

**Table 6.4:** Ethnicity cross tab by level of education

Ethnicity	Level of education			
	No formal qualifications	GCSE/O Level	A level/Further education	Undergraduate degree or higher
White British	82 (23.2%)	43 (12.2%)	87 (24.6%)	141 (39.9%)
Black African	4 (13.8%)	3 (10.3%)	17 (58.6%)	5 (17.2%)
Black Caribbean	18 (45%)	4 (10%)	13 (32.5%)	5 (12.5%)
White Other	8 (14.8%)	6 (11.1%)	17 (31.5%)	23 (42.6%)

Significant differences were found between ethnic groups by level of education ( $\chi^2(9, N=476)=33.51, p<0.001$ ). White British participants were educated to a range of educational levels where the majority held a university degree or higher, a quarter were educated to A level, nearly an eighth were educated to G.C.S.E/O level and nearly a quarter did not hold any formal qualifications. In contrast, the majority of Black African participants were educated to A level or equivalent and relatively smaller proportions held a degree, G.C.S.E/O level or no formal qualifications. Black Caribbean participants' educational levels were more dispersed as just over a third were educated to A level but nearly half did not hold any formal qualifications. The majority of White Other group participants held a degree, just over a third were educated to A level, leaving relatively few participants who were either educated to G.C.S.E/O level or did not hold any formal qualifications.

### 6.3.3 Demographic predictors of screening intentions

Mean intention and standard deviation (SD) scores of the ethnic groups are shown overleaf in table 6.5. A series of Univariate Analysis of Variance (ANOVA) tests were undertaken to identify the factors that influenced intentions to participate in screening as the demographic predictor variables were all categorical in nature. The results indicated there was a main effect of ethnicity on intentions to participate in screening ( $F(3,474)=8.340, p<0.001$ , partial  $\eta^2=0.050$ ). Sidak corrected pairwise comparisons indicated that the intentions of Black African participants were significantly lower than White British participants (mean

difference= -0.530,  $p < 0.001$ ) and the intentions of Black Caribbean participants were significantly lower than White British participants (mean difference= -0.360,  $p = 0.012$ ). The intentions of White Other and White British participants did not differ significantly (mean difference=0.140,  $p = 0.860$ ).

**Table 6.5:** Mean intentions & (SD) for screening by ethnicity

<b>Ethnicity</b>	<b>Mean (SD)</b>
White British	4.60 (0.65)
Black African	4.07 (0.83)
Black Caribbean	4.25 (0.57)
White Other	4.45 (0.76)

The impact of ethnicity on intentions was also examined through ANCOVA analysis, controlling for the individual SES indicators: SD, level of education and IMD quintile. The effect of ethnicity remained significant when SES factors were controlled although the effect size reduced marginally from when ethnicity was examined alone ( $F(3,473) = 6.478$ ,  $p < 0.001$ , partial  $\eta^2 = 0.039$ ). Sidak corrected pairwise comparisons once again showed that the intentions for screening of Black African (mean difference= -0.488,  $p = 0.001$ ) were significantly lower than the intentions of White British participants. However, the difference between the intentions of Black Caribbean and White British participants became marginally non-significant (mean difference= -0.298,  $p = 0.057$ ). None of the SES factors significantly affected intentions when entered alongside ethnicity, although the effect of SD was marginally non-significant ( $F(1,478) = 3.051$ ,  $p = 0.081$ ).

When the SES factors were examined individually, there was a main effect of SD on intentions to participate in screening ( $F(1,507) = 4.329$ ,  $p = 0.014$ , partial  $\eta^2 = 0.018$ ). Mean intention scores with SDs are presented overleaf in table 6.6. Sidak corrected pairwise comparisons indicated that the mean intentions of the most socially deprived (SD 2) group were significantly lower than the mean intentions of the least socially deprived (SD 0) group



(mean difference 0.289,  $p=0.020$ ). There were no differences between the intentions of the SD 1 group and all other SD groups. Level of education ( $F(3,505)=0.771$ ,  $p=0.511$ , partial  $\eta^2=0.005$ ) and IMD quintiles ( $F(3,506)=0.675$ ,  $p=0.568$ , partial  $\eta^2=0.004$ ) also did not have a significant impact on intentions for screening.

**Table 6.6:** Mean intention scores & (SD) by the various SES measures

<b>IMD quintile</b>	
1 Most deprived	4.52 (0.58)
2	4.54 (0.72)
3	4.44 (0.82)
4 Least deprived	4.66 (0.53)
<b>Social Deprivation</b>	
SD 0 Least deprived	4.61 (0.67)
SD 1	4.49 (0.65)
SD 2 Most deprived	4.30 (0.82)
<b>Level of education</b>	
No formal qualifications	4.43 (0.70)
GCSE/O Level	4.52 (0.56)
A level/Further education	4.53 (0.61)
Undergraduate degree or higher	4.57 (0.76)

### 6.3.4 Psychological predictors of screening intentions

Multiple regression was undertaken to examine which psychological factors within the TDF predicted intentions to participate in screening. Table 6.7, overleaf, displays the results of this analysis where significant results are in bold. The full model including all psychological variables accounted for 43.7% of the variance in intentions. Higher scores on beliefs about capabilities, beliefs about consequences, conceptual knowledge scales, and the single item that one's significant others would approve of one being screened were all associated with higher intentions for screening. In addition, a lower score on the practical barriers' scale also predicted higher screening intentions. Furthermore, Beliefs about Capabilities and Beliefs

about Consequences accounted for the most unique variance in screening intentions (see table 6.7, overleaf).

**Table 6.7:** Regression coefficients of the psychological predictors of screening intentions (n=507)

	Unstandardised Coefficients		Standardised Coefficients	P value	95.0% Confidence Interval for $\beta$		% Unique variance
	B	Std. Error	Beta		Lower Bound	Upper Bound	
<b>Beliefs about Capabilities</b>	<b>.380</b>	<b>.055</b>	<b>.329</b>	<b>&lt;.001</b>	<b>.272</b>	<b>.488</b>	<b>9.008</b>
Emotions	-.016	.045	-.016	.720	-.104	.072	0.027
Knowledge	-.007	.030	-.008	.830	-.066	.053	0.010
<b>Practical Barriers (environmental context)</b>	<b>-.106</b>	<b>.049</b>	<b>-.095</b>	<b>.030</b>	<b>-.201</b>	<b>-.010</b>	<b>0.980</b>
<b>Beliefs about Consequences</b>	<b>.549</b>	<b>.071</b>	<b>.389</b>	<b>&lt;.001</b>	<b>.408</b>	<b>.689</b>	<b>10.929</b>
Social and Religious Influence	-.046	.031	-.054	.142	-.107	.015	0.447
Memory, Attention & Decision	.046	.029	.059	.106	-.010	.102	0.541
<b>Conceptual Knowledge</b>	<b>.066</b>	<b>.028</b>	<b>.083</b>	<b>.020</b>	<b>.010</b>	<b>.121</b>	<b>1.121</b>
Behavioural regulation	.014	.049	.012	.774	-.082	.110	0.017
Perceived risk	-.042	.029	-.050	.148	-.098	.015	0.435
Screening would be pleasant	-.009	.024	-.016	.699	-.057	.038	0.031
Anticipated regret	.040	.032	.049	.214	-.023	.103	0.321
Early detection leads to successful treatment	-.057	.038	-.058	.133	-.132	.018	0.468

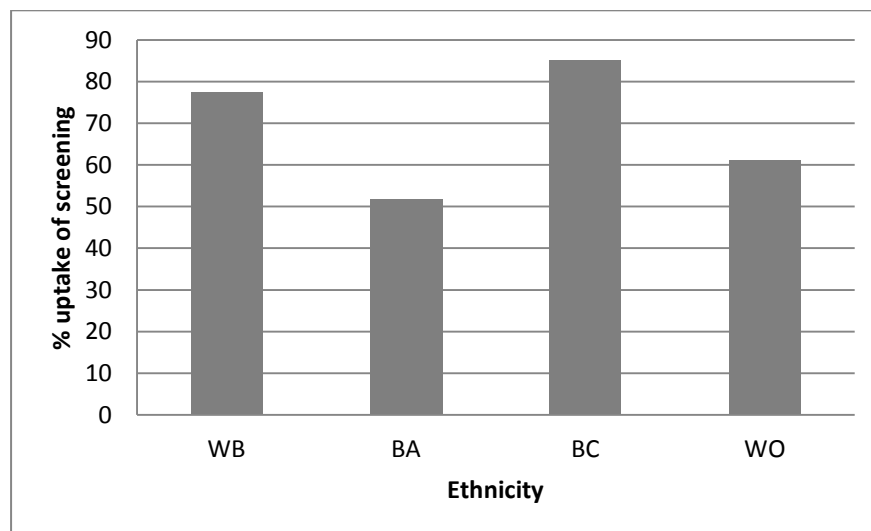
	Unstandardised Coefficients	Standardised Coefficients	95.0% Confidence Interval for B				
	B	Std. Error	Beta	P value	Lower Bound	Upper Bound	% Unique variance
Would need to complete FOBt at home	-.031	.023	-.049	.184	-.076	.015	0.366
Relief at normal result	-.025	.042	-.023	.564	-.108	.059	0.069
Important to keep healthy	-.033	.044	-.032	.457	-.120	.054	0.115
Would need regular bowel function to complete FOBt	.002	.021	.004	.910	-.040	.044	0.003
Bowel cancer is a hidden disease	-.035	.032	-.041	.269	-.097	.027	0.254
Important to look after self for family	-.024	.039	-.025	.531	-.100	.052	0.082
FOBt would better than sample in a pot	-.007	.025	-.010	.771	-.055	.041	0.018
Would be inappropriate to discuss bowel cancer screening with others	-.003	.030	-.004	.920	-.063	.057	0.002
<b>People close to me would approve of me doing the FOBt</b>	<b>.094</b>	<b>.038</b>	<b>.103</b>	<b>.015</b>	<b>.018</b>	<b>.169</b>	<b>1.218</b>
Religious beliefs say no to bowel cancer screening	.016	.040	.015	.688	-.062	.094	0.034
Religious beliefs would not impact my taking part in screening	-.025	.026	-.035	.344	-.077	.027	0.186
Bowel cancer is fatal	-.012	.037	-.012	.753	-.085	.061	0.021

### 6.3.5 Demographic predictors of screening uptake

A series of logistic regressions were undertaken to determine whether any of the demographic factors were statistically significant predictors of screening uptake. The findings are presented below for ethnicity and SES.

#### 6.3.5i Ethnicity

As displayed in figure 6.1 below, relatively high proportions of all ethnic groups took part in screening. Uptake was the highest amongst Black Caribbean (BC; 85%) and White British participants (WB; 77%) and the lowest amongst Black African participants (BA; 50%), followed by White Other participants (WO; 60%).



**Figure 6.1:** Percentage of participants across ethnic groups who subsequently took part in screening

Logistic regression indicated that ethnicity was a significant predictor of screening uptake where Black African and White Other participants were significantly less likely to take part in screening compared to White British participants. Black Caribbean participants did not statistically significantly differ in their likelihood of screening uptake compared to the White

British group despite a positive odds ratio. The results from this analysis are presented in table 6.8, below.

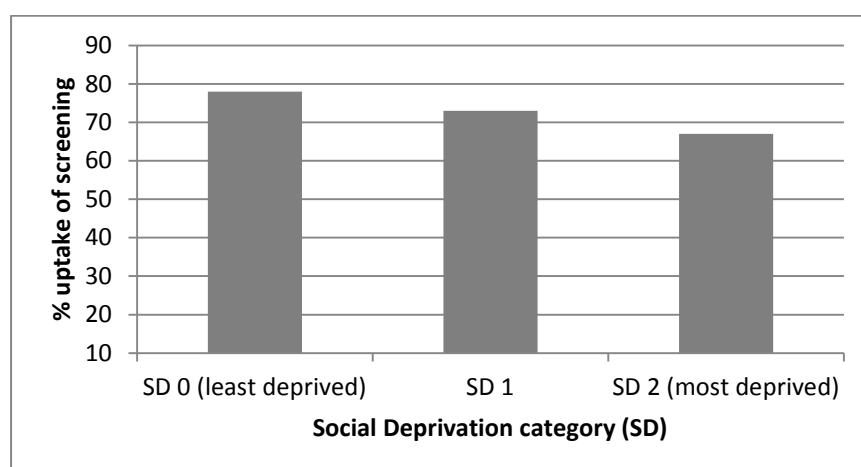
**Table 6.8:** *Ethnicity as a predictor of screening uptake*

Ethnicity*	B	Wald $\chi^2$	P	Odds ratio	95% Confidence interval	
					Lower bound	Upper bound
Black African	-1.146	8.523	0.004	0.318	0.147	0.686
Black Caribbean	0.520	1.273	0.259	1.681	0.692	4.146
White Other	-0.810	7.142	0.008	0.445	0.246	0.806

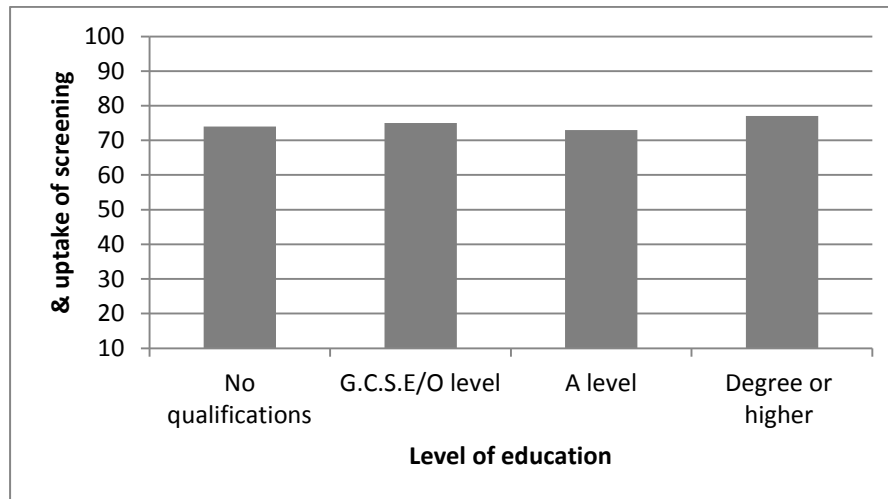
\* Note: White British participants were the reference group

### 6.3.5ii SES

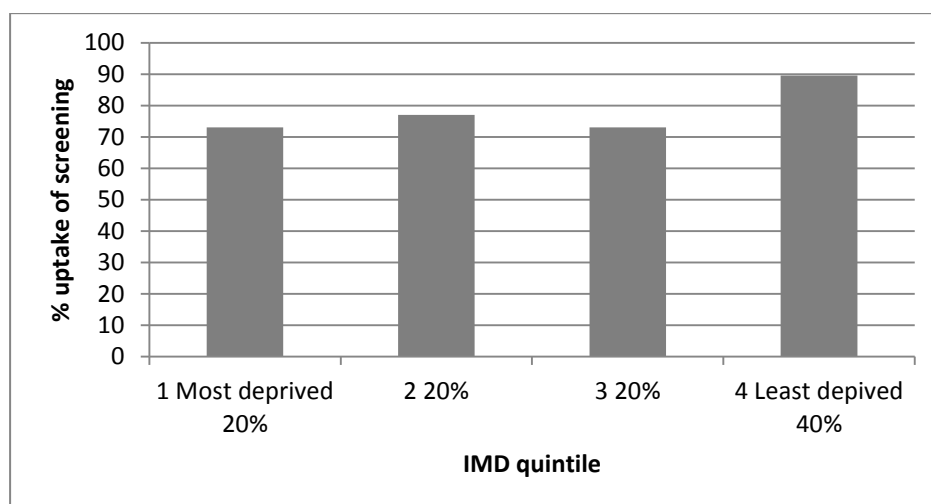
Uptake of screening was generally high and similar across different SES groups when SD, level of education and IMD quintiles were used as SES indicators. Figures 6.2, 6.3 and 6.4 below illustrate uptake of screening across SD, level of education and IMD quintiles, respectively.



**Figure 6.2:** *Percentage of participants across SES groups (SD) who subsequently took part in screening*



**Figure 6.3:** Percentage of participants across SES groups (level of education) who subsequently took part in screening



**Figure 6.4:** Percentage of participants across SES groups (IMD quintile) who subsequently took part in screening

Logistic regressions were run individually for each SES indicator revealing that SD, IMD quintile and level of education were not significant predictors of screening uptake (see table 6.9, below). Although it was initially planned to examine uptake of screening by ethnicity whilst controlling for SES, as none of the SES factors were individually associated with screening uptake, this analysis was not pursued.

**Table 6.9: SES as a predictor of screening uptake**

SES indicators	$\beta$	Wald $\chi^2$	P	Odds ratio	95% Confidence Intervals	
					Lower bound	Upper bound
SD*						
SD 0 (least deprived)	0.140	0.166	0.684	1.150	0.586	2.256
SD 1	0.517	0.357	0.147	1.677	0.834	3.375
Level of education^						
G.C.S.E/O level	0.191	0.250	0.617	1.210	0.573	2.557
A level	-0.042	0.021	0.885	0.959	0.546	1.686
Degree and higher	0.140	0.253	0.615	1.150	0.668	1.980
IMD quintile <sup>†</sup>						
(2) Most deprived 20%	-1.193	2.251	0.134	0.303	0.064	1.441
(3) Most deprived 20%	-1.005	1.717	0.190	0.366	0.081	1.646
Least deprived 40%	-1.161	2.312	0.128	0.313	0.070	1.399

\*SD reference category: SD 2 (most deprived)

^Level of education reference category: no formal qualifications

†IMD quintile reference category: Most deprived 20%

### 6.3.5iii Gender

For completeness of analysis, screening uptake was also assessed by gender. Overall, a greater proportion of women participated in screening than men (79.1% and 69.6%, respectively). Gender was also found to be a significant predictor of screening uptake in the results of the binary logistic regression where women were significantly more likely than men to take part in screening (Wald  $\chi^2=4.569$ ,  $p=0.033$ , OR: 1.567, 95% C.I 1.038 – 2.367).

### 6.3.6 Psychological predictors of screening uptake

As many psychological theories postulate behavioural intention as the proximal determinant of behaviour, whether intention predicted screening uptake was assessed first. As expected,



intention emerged as a significant predictor of screening uptake (Wald  $\chi^2 = 39.608$ ,  $p < 0.001$ , OR 2.959, 95% confidence intervals (C.I) 2.111 - 4.148). As intention was a strong predictor of screening, multicollinearity, or extent of correlation, with the other psychological variables of the TDF was assessed. Intention was found to be moderately and significantly correlated with both the Beliefs about Capabilities ( $r = 0.571$ ,  $p < 0.001$ ) and Beliefs about Consequences domains ( $r = 0.576$ ,  $p < 0.001$ ). Moreover, the two domains were also found to be similarly correlated amongst themselves ( $r = 0.556$ ,  $p < 0.001$ ). Binary logistic regression to determine the psychological predictors of screening uptake was thus conducted once including intention and once without. The results presented below are based on the full sample of 507 participants.

As displayed in table 6.10, when intentions and socio-demographics were not included in the analysis, Beliefs about Capabilities and Behavioural Regulation domains emerged as significant predictors of screening uptake, where higher scores on these scales increased the likelihood of uptake. However, when intention was added to the model, the Beliefs about Capabilities domain was no longer a significant predictor of screening uptake (see table 6.11). As well as intention, the only other significant predictor of screening uptake was the Behavioural Regulation domain.

The final part of analysis in this section on the psychological predictors of screening uptake examined the role of previous screening uptake. The analysis also included all the psychological variables, including intention. The results are displayed overleaf in table 6.12. As depicted by the table, the results changed very little except that previous uptake of screening also emerged as a significant predictor of screening uptake in the current study. Moreover, those who had previously not responded or had not been invited to take part in screening were significantly less likely to take part in screening compared to people who had previously taken part in screening.

**Table 6.10:** *Psychological predictors of screening uptake (excluding intention)*

<b>Psychological variables</b>	<b>B</b>	<b>Wald <math>\chi^2</math></b>	<b>P value</b>	<b>Odds ratio</b>	<b>95% C.I.</b>	
					<b>Lower</b>	<b>Upper</b>
Perceived risk	0.143	1.066	0.302	1.154	0.879	1.515
Screening would be pleasant	0.118	0.967	0.325	1.125	0.890	1.423
Anticipated regret	0.022	0.021	0.884	1.022	0.759	1.377
Early detection leads to successful treatment	-0.083	0.204	0.652	0.920	0.642	1.319
Would need to complete FOBt at home	0.120	1.155	0.283	1.128	0.906	1.404
Relief at normal result	0.062	0.102	0.750	1.064	0.726	1.561
Bowel cancer is fatal	0.015	0.007	0.931	1.015	0.717	1.439
Important to keep healthy	-0.159	0.556	0.456	0.853	0.562	1.296
Would need regular bowel function to complete FOBt	-0.025	0.056	0.812	0.975	0.793	1.199
Bowel cancer is a hidden disease	-0.163	1.046	0.306	0.850	0.622	1.161
Religious beliefs would not impact my taking part in screening	0.155	1.624	0.203	1.167	0.920	1.480
Important to look after self for family	-0.078	0.179	0.672	0.925	0.643	1.329
FOBt would better than sample in a pot	-0.191	2.240	0.134	0.826	0.644	1.061

Psychological variables	B	Wald $\chi^2$	P value	Odds ratio	95% C.I.	
					Lower	Upper
Would be inappropriate to discuss bowel cancer screening with others	0.017	0.014	0.905	1.017	0.771	1.342
People close to me would approve of me completing the FOBt	0.301	2.918	0.088	1.352	0.957	1.909
Religious beliefs say no to bowel cancer screening	0.134	0.488	0.485	1.143	0.785	1.665
<b>Beliefs about Capabilities</b>	<b>0.540</b>	<b>4.598</b>	<b>0.032</b>	<b>1.717</b>	<b>1.048</b>	<b>2.813</b>
Emotions	0.186	0.727	0.394	1.204	0.785	1.847
Knowledge	-0.175	1.360	0.244	0.840	0.626	1.126
Practical Barriers (environmental context)	-0.265	1.485	0.223	0.767	0.501	1.175
Beliefs about Consequences	0.046	0.019	0.891	1.047	0.542	2.022
Social and Religious Influence	-0.146	0.900	0.343	0.864	0.639	1.169
Memory, Attention & Decision	0.087	0.371	0.542	1.091	0.824	1.445
Conceptual Knowledge	0.191	2.068	0.150	1.210	0.933	1.569
<b>Behavioural regulation</b>	<b>0.539</b>	<b>5.668</b>	<b>0.017</b>	<b>1.714</b>	<b>1.100</b>	<b>2.671</b>

**Table 6.11:** Psychological predictors of screening uptake, including intention

Psychological variables	B	Wald $\chi^2$	P value	Odds ratio	95% C.I.	
					Lower	Upper
Perceived risk	0.182	1.673	0.196	1.199	0.911	1.579
Screening would be pleasant	0.126	1.067	0.302	1.134	0.893	1.440
Anticipated regret	-0.026	0.026	0.871	0.974	0.712	1.334
Early detection leads to successful treatment	-0.032	0.028	0.867	0.969	0.668	1.405
Would need to complete FOBt at home	0.153	1.786	0.181	1.165	0.931	1.458
Relief at normal result	0.102	0.256	0.613	1.107	0.746	1.644
Bowel cancer is fatal	0.032	0.032	0.858	1.033	0.723	1.475
Important to keep healthy	-0.121	0.302	0.583	0.886	0.576	1.364
Would need regular bowel function to complete FOBt	-0.016	0.023	0.879	0.984	0.797	1.214
Bowel cancer is a hidden disease	-0.131	0.641	0.423	0.877	0.637	1.209
Religious beliefs would not impact my taking part in screening	0.181	2.174	0.140	1.199	0.942	1.526
Important to look after self for family	-0.076	0.157	0.692	0.927	0.635	1.351
FOBt would better than sample in a pot	-0.178	1.902	0.168	0.837	0.650	1.078
Would be inappropriate to discuss bowel cancer screening with others	0.013	0.008	0.928	1.013	0.762	1.348

<b>Psychological variables</b>	<b>B</b>	<b>Wald <math>\chi^2</math></b>	<b>P value</b>	<b>Odds ratio</b>	<b>95% C.I.</b>	
					<b>Lower</b>	<b>Upper</b>
People close to me would approve of me completing the FOBt	0.205	1.251	0.263	1.228	0.857	1.760
Religious beliefs say no to bowel cancer screening	0.106	0.289	0.591	1.112	0.756	1.635
Beliefs about Capabilities	0.225	0.647	0.421	1.252	0.724	2.168
Emotions	0.224	0.998	0.318	1.251	0.806	1.943
Knowledge	-0.194	1.576	0.209	0.824	0.609	1.115
Practical Barriers (environmental context)	-0.150	0.430	0.512	0.860	0.549	1.348
Beliefs about Consequences	-0.516	1.853	0.173	0.597	0.284	1.255
Social and Religious Influence	-0.109	0.484	0.487	0.897	0.660	1.219
Memory, Attention & Decision	0.041	0.079	0.779	1.042	0.784	1.384
Conceptual Knowledge	0.135	0.988	0.320	1.144	0.877	1.493
<b>Behavioural regulation</b>	<b>0.538</b>	<b>5.470</b>	<b>0.019</b>	<b>1.712</b>	<b>1.091</b>	<b>2.687</b>
<b>Intentions</b>	<b>0.930</b>	<b>17.402</b>	<b>&lt;0.001</b>	<b>2.535</b>	<b>1.637</b>	<b>3.924</b>

**Table 6.12:** Psychological predictors of screening uptake, including intention and past behaviour.

Psychological variables	B	Wald $\chi^2$	P value	Odds ratio	95% C.I.	
					Lower	Upper
Perceived risk	0.212	2.100	0.147	1.236	0.928	1.648
Screening would be pleasant	0.158	1.525	0.217	1.171	0.912	1.503
Anticipated regret	0.047	0.081	0.776	1.048	0.759	1.446
Early detection leads to successful treatment	-0.133	0.461	0.497	.875	0.596	1.286
Would need to complete FOBt at home	0.144	1.448	0.229	1.155	0.914	1.459
Relief at normal result	0.095	0.189	0.664	1.099	0.718	1.683
Bowel cancer is fatal	0.126	0.464	0.496	1.135	0.789	1.632
Important to keep healthy	-0.043	0.035	0.852	0.958	0.612	1.500
Would need regular bowel function to complete FOBt	-0.022	0.040	0.841	0.978	0.787	1.216
Bowel cancer is a hidden disease	0.016	0.009	0.926	1.016	0.730	1.414
Religious beliefs would not impact my taking part in screening	0.163	1.572	0.210	1.178	0.912	1.520
Important to look after self for family	-0.060	0.091	0.762	0.941	0.636	1.393
FOBt would better than sample in a pot	-0.205	2.343	0.126	0.815	0.627	1.059
Would be inappropriate to discuss bowel cancer screening with others	0.046	0.088	0.767	1.047	0.773	1.417

Psychological variables	B	Wald $\chi^2$	P value	Odds ratio	95% C.I.	
					Lower	Upper
People close to me would approve of me completing the FOBt	0.308	2.476	0.116	1.361	0.927	1.998
Religious beliefs say no to bowel cancer screening	0.103	0.252	0.616	1.109	0.741	1.660
Beliefs about Capabilities	-0.014	0.002	0.962	0.987	0.565	1.723
Emotions	0.277	1.423	0.233	1.319	0.837	2.078
Knowledge	-0.098	0.364	0.546	0.907	0.660	1.246
Practical Barriers (environmental context)	-0.088	0.136	0.713	0.916	0.573	1.463
Beliefs about Consequences	-0.503	1.666	0.197	0.605	0.282	1.298
Social and Religious Influence	-0.188	1.359	0.244	0.829	0.605	1.136
Memory, Attention & Decision	-0.033	0.047	0.827	0.968	0.722	1.297
Conceptual Knowledge	0.138	0.975	0.323	1.148	0.873	1.510
<b>Behavioural regulation</b>	<b>0.562</b>	<b>5.652</b>	<b>0.017</b>	<b>1.755</b>	<b>1.104</b>	<b>2.789</b>
<b>Intentions</b>	<b>0.733</b>	<b>10.027</b>	<b>0.002</b>	<b>2.081</b>	<b>1.322</b>	<b>3.275</b>
<b>Past behaviour*</b> (*reference group: previous screening completers)						
<b>Did not respond</b>	<b>-1.528</b>	<b>26.988</b>	<b>&lt;0.001</b>	<b>0.217</b>	<b>0.122</b>	<b>0.386</b>
<b>Not yet invited</b>	<b>-0.717</b>	<b>5.057</b>	<b>0.025</b>	<b>0.488</b>	<b>0.261</b>	<b>0.912</b>

### **6.3.7 Variation in psychological beliefs by ethnicity and SES**

#### **6.3.7i Ethnicity**

A one way ANOVA was conducted to examine whether there were any differences in the beliefs held by the four ethnic groups. Table 6.13 displays the mean and (standard deviation) scores alongside the ANOVA results for the TDF scales and single items. Domains and beliefs that differed significantly across ethnic groups are in bold and specific differences between ethnic groups that were assessed through Sidak corrected pairwise comparisons are discussed in the text below. Although the results revealed a number of domains and single beliefs differed across ethnic groups, effect sizes ( $\eta^2$ ), on the whole, were very small (see table 6.13).

In relation to ‘Beliefs about Capabilities’, White British participants had perceived themselves to be significantly more capable than did White other participants (mean difference 0.224,  $p=0.049$ ). There were no significant differences in ‘Beliefs about Capabilities’ scores between Black African, Black Caribbean and White British participants.

In terms of ‘Emotions’, White British participants perceived significantly lower negative emotions about completing the FOBt, including fear of CRC, embarrassment, fear of a cancer diagnosis as well as concerns about potential mess, storage and postage, than Black African participants (mean difference 0.341,  $p=0.041$ ). There were no significant differences in ‘Emotions’ scores between Black Caribbean, White British participants and White Other participants.

When it came to knowledge about CRC and the screening programme, White British participants had significantly lower levels of knowledge compared to Black African (mean difference 0.535,  $p=0.004$ ) and Black Caribbean participants (mean difference 0.654,  $p<0.001$ ). Knowledge about CRC and screening did not differ by any other ethnic group.



However, in relation to 'Conceptual Knowledge', Black African participants had significantly lower levels of knowledge about the incidence of CRC in the UK and overall conceptual understanding about screening compared to White British (mean difference 0.569,  $p=0.003$ ) and Black Caribbean participants (mean difference 0.554,  $p=0.039$ ).

In relation to 'Practical barriers', participants on the whole perceived few barriers to completing the FOBt although White British participants had significantly higher scores than Black African participants (mean difference 0.380,  $p=0.005$ ).

Differences were apparent on the 'Social and Religious Influence' domain that included items about preference for GP approval of screening, being more likely to complete the FOBt if one knew lots of others had done so and religious beliefs as motivation for looking after one's health. White British participants scored significantly lower than Black African (mean difference 0.687,  $p<0.001$ ) and Black Caribbean participants (mean difference 0.396,  $p=0.014$ ), indicating lower endorsement of social and religious influences. White Other participants also had significantly lower scores on this domain than Black African participants (mean difference 0.553,  $p=0.012$ ).

With regards to the 'Behavioural regulation' domain that was concerned with the ability to plan the completion of the FOBt and not requiring any assistance, although the initial ANOVA results indicated a significant difference between ethnic groups, post hoc Sidak corrected comparisons indicated that the differences between individual ethnic groups were marginally non-significant. White British participants had marginally higher scores on this domain than Black African (mean difference 0.267,  $p=0.076$ ), Black Caribbean (mean difference 0.235,  $p=0.067$ ) and White Other participants (mean difference 0.204,  $p=0.067$ ).

Several individual beliefs also differed by ethnicity. Regarding perceived risk, Black African participants perceived themselves to be at significantly lower risk of getting CRC than other

people their age than did Black Caribbean participants (mean difference 0.726,  $p=0.001$ ) and White British participants (mean difference 0.417,  $p=0.045$ ).

Taking part in CRC screening was perceived as significantly less pleasant by White British participants compared to Black African (mean difference 1.108,  $p<0.001$ ) and Black Caribbean participants (mean difference 0.696,  $p=0.001$ ). Furthermore, pleasantness ratings were also significantly lower for White Other participants compared to Black African participants (mean difference 0.917,  $p=0.002$ ).

In terms of anticipated regret of not completing screening, Black African participants perceived significantly lower anticipated regret than Black Caribbean (mean difference 0.682,  $p=0.004$ ), White British (mean difference 0.828,  $p<0.001$ ) and White Other participants (mean difference 0.698,  $p=0.001$ ).

Both White British and White Other participants believed that CRC was a fatal disease more strongly than Black African and Black Caribbean participants and these differences were mostly significant: White British Vs Black African (mean difference 0.347,  $p=0.045$ ), White British Vs Black Caribbean (mean difference 0.370,  $p=0.006$ ) and, White Other Vs Black African (mean difference 0.391,  $p=0.066$  marginally non significant) and White Other Vs Black Caribbean (mean difference 0.414,  $p=0.019$ ).

In relation to religious beliefs and screening, Black African participants had significantly lower endorsement that their beliefs would not influence their decision to be screened than White British participants (mean difference 0.518,  $p=0.018$ ). Moreover, on a separate item, Black African participants endorsed the view that one's religious beliefs would prevent one from being screened, significantly more strongly than White British participants (mean difference 0.424,  $p=0.004$ ). In addition, White Other participants also endorsed this item more strongly than White British participants (mean difference 0.269,  $p=0.025$ ).

Relating to the collection of the faecal sample, White Other participants tended to prefer providing a faecal sample in a pot as opposed to the FOBt compared to White British people (mean difference 0.385,  $p=0.033$ ).

In relation to the appropriateness of discussing CRC screening with others, Black African participants thought it would be significantly more appropriate to discuss screening compared to White British (mean difference 0.579,  $p=0.003$ ) and White Other participants (mean difference 0.636,  $p=0.008$ ). However, Black African participants rated the approval of people close to them about taking part in CRC screening significantly lower than White British participants (mean difference 0.619,  $p<0.001$ ), but higher than White Other participants (mean difference 0.552,  $p=0.006$ ).

**Table 6.13: Ethnicity by TDF and psychological variables**

Psychological variables	Mean (S.D) by Ethnicity (n=478)				ANOVA		
	Black African	Black Caribbean	White British	White Other	F	P value	$\eta^2$
<b>Perceived risk</b>	<b>2.72 (0.96)</b>	<b>3.45 (0.85)</b>	<b>3.14 (0.77)</b>	<b>3.16 (0.90)</b>	<b>4.554</b>	<b>0.004</b>	<b>0.028</b>
<b>Screening would be pleasant</b>	<b>3.86 (1.09)</b>	<b>3.45 (1.24)</b>	<b>2.75 (1.05)</b>	<b>2.95 (1.15)</b>	<b>13.240</b>	<b>&lt;0.001</b>	<b>0.077</b>
<b>Anticipated regret</b>	<b>3.79 (1.35)</b>	<b>4.48 (0.75)</b>	<b>4.62 (0.76)</b>	<b>4.49 (0.88)</b>	<b>9.359</b>	<b>&lt;0.001</b>	<b>0.056</b>
Early detection leads to successful treatment	4.28 (0.88)	4.48 (0.64)	4.33 (0.65)	4.33 (0.64)	0.668	0.572	0.004
Would need to complete FOBt at home	4.07 (0.84)	3.95 (0.85)	3.85 (1.11)	3.75 (1.17)	0.672	0.569	0.004
Relief at normal result	4.41 (0.73)	4.68 (0.47)	4.64 (0.65)	4.55 (0.60)	1.513	0.210	0.009
<b>Bowel cancer is fatal</b>	<b>4.17 (0.89)</b>	<b>4.15 (0.74)</b>	<b>4.52 (0.66)</b>	<b>4.56 (0.54)</b>	<b>5.945</b>	<b>0.001</b>	<b>0.036</b>
Important to keep healthy	4.48 (0.83)	4.55 (0.75)	4.65 (0.63)	4.67 (0.51)	0.900	0.441	0.006
<b>Would need regular bowel function to complete FOBt</b>	<b>3.45 (1.09)</b>	<b>3.33 (1.14)</b>	<b>2.99 (1.18)</b>	<b>3.33 (0.98)</b>	<b>3.095</b>	<b>0.027</b>	<b>0.019</b>
Bowel cancer is a hidden disease	4.17 (0.73)	3.95 (0.85)	3.09 (1.16)	4.11 (0.81)	1.363	0.254	0.009
Religious beliefs would not impact my taking part in screening	3.97 (1.15)	4.33 (0.83)	4.48 (0.87)	4.35 (1.02)	3.312	0.020	0.021
Important to look after self for family	4.38 (0.68)	4.58 (0.64)	4.50 (0.72)	4.49 (0.69)	0.433	0.729	0.003
<b>FOBt would better than sample in a pot</b>	<b>3.69 (0.85)</b>	<b>3.60 (1.06)</b>	<b>3.88 (0.93)</b>	<b>2.49 (1.09)</b>	<b>3.392</b>	<b>0.018</b>	<b>0.021</b>

	Mean (S.D) by Ethnicity (n=478)				ANOVA		
	Black African	Black Caribbean	White British	White Other	F	P value	$\eta^2$
<b>Psychological variables</b>							
<b>Would be inappropriate to discuss bowel cancer screening with others</b>	<b>2.34 (1.20)</b>	<b>1.95 (0.90)</b>	<b>1.77 (0.82)</b>	<b>1.71 (0.85)</b>	<b>4.676</b>	<b>0.003</b>	<b>0.029</b>
<b>People close to me would approve of me completing the FOBt</b>	<b>3.79 (1.01)</b>	<b>4.23 (0.70)</b>	<b>4.41 (0.71)</b>	<b>4.35 (0.70)</b>	<b>6.843</b>	<b>&lt;0.001</b>	<b>0.042</b>
<b>Religious beliefs say no to bowel cancer screening</b>	<b>1.83 (0.93)</b>	<b>1.60 (0.67)</b>	<b>1.40 (0.57)</b>	<b>1.67 (0.88)</b>	<b>6.546</b>	<b>&lt;0.001</b>	<b>0.040</b>
<b>Beliefs about Capabilities</b>	<b>4.14 (0.67)</b>	<b>4.35 (0.49)</b>	<b>4.40 (0.57)</b>	<b>4.18 (0.70)</b>	<b>3.791</b>	<b>0.010</b>	<b>0.023</b>
<b>Emotions</b>	<b>2.60 (0.62)</b>	<b>2.42 (0.63)</b>	<b>2.26 (0.67)</b>	<b>2.42 (0.59)</b>	<b>3.446</b>	<b>0.017</b>	<b>0.021</b>
<b>Knowledge</b>	<b>3.51 (0.82)</b>	<b>3.63 (0.56)</b>	<b>2.97 (0.82)</b>	<b>3.19 (0.88)</b>	<b>11.347</b>	<b>&lt;0.001</b>	<b>0.067</b>
<b>Practical Barriers (environmental context)</b>	<b>1.90 (0.82)</b>	<b>1.67 (0.61)</b>	<b>1.52 (0.58)</b>	<b>1.64 (0.56)</b>	<b>4.384</b>	<b>0.005</b>	<b>0.027</b>
Beliefs about Consequences	4.33 (0.67)	4.36 (0.53)	4.51 (0.46)	4.48 (0.47)	2.266	0.080	0.014
<b>Social and Religious Influence</b>	<b>3.63 (0.64)</b>	<b>3.34 (0.66)</b>	<b>2.95 (0.82)</b>	<b>3.08 (0.61)</b>	<b>9.427</b>	<b>&lt;0.001</b>	<b>0.056</b>
Memory, Attention & Decision	2.91 (0.60)	2.74 (0.76)	2.66 (0.89)	2.75 (0.85)	0.904	0.439	0.006
<b>Conceptual Knowledge</b>	<b>1.62 (0.78)</b>	<b>2.18 (0.78)</b>	<b>2.19 (0.84)</b>	<b>2.05 (0.89)</b>	<b>4.374</b>	<b>0.005</b>	<b>0.027</b>
<b>Behavioural regulation</b>	<b>4.16 (0.52)</b>	<b>4.19 (0.67)</b>	<b>4.42 (0.52)</b>	<b>4.22 (0.69)</b>	<b>5.289</b>	<b>0.001</b>	<b>0.032</b>

### **6.3.7ii Variation in psychological beliefs by SES**

One way ANOVAs were conducted for each SES indicator to examine whether there were any differences in beliefs by social deprivation, level of education and IMD quintile as shown in tables 6.14, 6.15 and 6.16, respectively. Domains and beliefs that differed significantly across groups are in bold and specific differences that were assessed through Sidak corrected pairwise comparisons are discussed within the text. As with the ethnicity section, effect sizes ( $\eta^2$ ) representing the magnitude of differences between groups remained very small. Patterning of each SES indicator will now be discussed, beginning with Social Deprivation (SD).

#### **6.3.7ii.a SD**

The ‘Knowledge’ domain, concerning knowledge of CRC and screening, was found to significantly vary by SD. Those in the least deprived group, SD 0, had significantly higher levels of knowledge than those in the intermediate SD 1 category (mean difference 0.265,  $p=0.002$ ) and those in the most deprived SD 2 category (mean difference 0.719,  $p<0.001$ ). In addition, the SD 1 group had significantly higher levels of knowledge than the most deprived SD 2 group (mean difference 0.454,  $p=0.001$ ). Similarly, in terms of ‘Conceptual knowledge’, the SD 0 group had significantly higher levels of conceptual knowledge than the SD 1 (mean difference 0.268,  $p=0.002$ ) and SD 2 groups (mean difference 0.545,  $p<0.001$ ).

In relation to the ‘Practical Barriers’ domain that included barriers to FOBt completion such as mobility problems, too many other life issues and not being able to complete due to disgust, the most deprived SD 2 group experienced greater barriers than the least deprived SD 0 group (mean difference 0.220,  $p=0.044$ ). Furthermore, the intermediate SD 1 group

also experienced significantly greater barriers than the least deprived SD 0 group (mean difference 0.221,  $p<0.001$ ).

For the domain regarding 'Social and religious influence', the least deprived SD 0 group had significantly lower scores than both the SD 1 (mean difference -0.282,  $p<0.001$ ) and SD 2 groups (mean difference 0.498,  $p<0.001$ ) indicating that they were less influenced by these factors.

In the 'Memory, attention and decision' domain including items relating to memory difficulties in completing the FOBt, people in the most deprived SD 2 group had significantly higher scores than both the SD 1 (mean difference 0.453,  $p=0.002$ ) and SD 0 groups (mean difference 0.633,  $p<0.001$ ), indicating greater memory difficulties.

For the individual items, perceived pleasantness of the FOBt was significantly lower for the least deprived SD 0 group than the intermediate SD 1 (0.497,  $p<0.001$ ) and most deprived SD 2 groups (0.886,  $p<0.001$ ). Differences in anticipated regret of not completing the FOBt was only found to be significant between the SD 1 and SD 0 group, where the former had higher levels of anticipated regret (mean difference 0.230,  $p=0.009$ ). In addition, the SD 1 group also had higher scores than the SD 0 group on the item relating to CRC being a fatal disease (mean difference 0.167,  $p=0.029$ ). Furthermore, the SD 1 group had lower scores than the SD 0 group on the item concerning motivation to keep healthy (mean difference 0.147,  $p=0.047$ ). SD groups also differed on the item regarding the need to have regular bowel function for one to complete the FOBt. The most deprived SD 2 group had significantly higher scores on this item than the least deprived SD 0 group (mean difference 0.588,  $p=0.004$ ), suggesting perhaps they had more bowel problems. The final item to differ by SD stipulated that one's religious beliefs would not influence one's decision to take part in screening or not. Scores of the most deprived SD 2 group were significantly lower than the least deprived SD 0 group (mean difference 0.385,  $p=0.031$ ).

**Table 6.14:** Social Deprivation by TDF and psychological variables

Psychological variables	Mean (S.D) by Social Deprivation (n=507)			ANOVA		
	SD 0 Least deprived	SD 1 Intermediate deprived	SD 2 Most deprived	F	P value	$\eta^2$
Perceived risk	3.05 (0.73)	3.17 (0.84)	3.33 (0.94)	2.670	0.070	0.010
<b>Screening would be pleasant</b>	<b>2.58 (1.03)</b>	<b>3.08 (1.13)</b>	<b>3.47 (1.06)</b>	<b>19.155</b>	<b>&lt;0.001</b>	<b>0.071</b>
<b>Anticipated regret</b>	<b>4.68 (0.62)</b>	<b>4.45 (0.94)</b>	<b>4.41 (0.98)</b>	<b>5.175</b>	<b>0.006</b>	<b>0.020</b>
Early detection leads to successful treatment	4.31 (0.64)	4.33 (0.69)	4.39 (0.79)	0.288	0.750	0.001
Would need to complete FOBt at home	3.77 (1.12)	3.89 (1.07)	3.94 (0.94)	0.922	0.399	0.004
Relief at normal result	4.67 (0.60)	4.59 (0.66)	4.65 (0.60)	1.043	0.353	0.004
<b>Bowel cancer is fatal</b>	<b>4.56 (0.56)</b>	<b>4.40 (0.76)</b>	<b>4.31 (0.80)</b>	<b>4.685</b>	<b>0.010</b>	<b>0.018</b>
<b>Important to keep healthy</b>	<b>4.72 (0.52)</b>	<b>4.57 (0.73)</b>	<b>4.59 (0.73)</b>	<b>3.028</b>	<b>0.049</b>	<b>0.012</b>
<b>Would need regular bowel function to complete FOBt</b>	<b>2.94 (1.11)</b>	<b>3.13 (1.16)</b>	<b>3.53 (1.14)</b>	<b>5.563</b>	<b>0.004</b>	<b>0.022</b>
Bowel cancer is a hidden disease	4.15 (0.67)	4.05 (0.90)	4.27 (0.60)	1.987	0.138	0.008
<b>Religious beliefs would not impact my taking part in screening</b>	<b>4.51 (0.80)</b>	<b>4.35 (0.97)</b>	<b>4.12 (1.32)</b>	<b>3.850</b>	<b>0.022</b>	<b>0.015</b>
Important to look after self for family	4.57 (0.63)	4.45 (0.72)	4.47 (0.82)	1.835	0.161	0.007
FOBt would better than sample in a pot	3.73 (0.92)	3.76 (1.02)	4.06 (0.88)	2.422	0.090	0.010



	Mean (S.D) by Social Deprivation (n=507)			ANOVA		
	SD 0 Least deprived	SD 1 Intermediate deprived	SD 2 Most deprived	F	P value	$\eta^2$
<b>Psychological variables</b>						
Would be inappropriate to discuss bowel cancer screening with others	1.75 (0.85)	1.85 (0.87)	2.08 (1.08)	2.870	0.058	0.011
People close to me would approve of me completing the FOBt	4.40 (0.61)	4.31 (0.81)	4.33 (0.88)	0.909	0.404	0.004
Religious beliefs say no to bowel cancer screening	1.42 (0.62)	1.50 (0.65)	1.55 (0.74)	1.337	0.264	0.005
Beliefs about Capabilities	4.39 (0.56)	4.31 (0.59)	4.35 (0.66)	1.003	0.368	0.004
Emotions	2.28 (0.61)	2.34 (0.69)	2.28 (0.66)	.440	0.644	0.002
<b>Knowledge</b>	<b>2.89 (0.82)</b>	<b>3.15 (0.81)</b>	<b>3.61 (0.72)</b>	<b>17.382</b>	<b>&gt;0.001</b>	<b>0.065</b>
<b>Practical Barriers (environmental context)</b>	<b>1.44 (0.50)</b>	<b>1.66 (0.67)</b>	<b>1.66 (0.58)</b>	<b>8.399</b>	<b>&gt;0.001</b>	<b>0.032</b>
Beliefs about Consequences	4.51 (0.43)	4.47 (0.49)	4.46 (0.61)	.426	0.654	0.002
<b>Social and Religious Influence</b>	<b>2.85 (0.74)</b>	<b>3.13 (0.83)</b>	<b>3.35 (0.74)</b>	<b>11.555</b>	<b>&gt;0.001</b>	<b>0.044</b>
<b>Memory, Attention &amp; Decision</b>	<b>2.54 (0.90)</b>	<b>2.72 (0.81)</b>	<b>3.18 (0.67)</b>	<b>11.606</b>	<b>&gt;0.001</b>	<b>0.044</b>
<b>Conceptual Knowledge</b>	<b>2.32 (0.78)</b>	<b>2.05 (0.86)</b>	<b>1.78 (0.92)</b>	<b>10.958</b>	<b>&gt;0.001</b>	<b>0.042</b>
Behavioural regulation	2.85 (0.36)	2.89 (0.37)	2.90 (0.50)	0.847	0.429	0.003

### **6.3.7ii.b Level of education**

‘Knowledge’ of CRC and the screening programme was significantly higher for those with a degree than those with no formal qualification (mean difference 0.537,  $p<0.001$ ) and those with G.C.S.E/O level qualifications (mean difference 0.358,  $p=0.019$ ). People with A level or equivalent qualifications had higher levels of knowledge than those with no formal qualifications (mean difference 0.331,  $p=0.007$ ). In terms of conceptual knowledge, this was significantly greater for those with a degree than those with no formal qualifications (mean difference 0.307,  $p<0.001$ ).

In relation to the ‘social and religious influence’ domain, those with a degree had lower scores than those with A level or equivalent qualifications (mean difference 0.304,  $p=0.004$ ) and those with no formal qualifications (mean difference 0.400,  $p<0.001$ ). There were no significant differences between participants who had G.C.S.E/O level qualifications and those with any other level of education on the ‘social and religious influence’ domain.

Participants with no formal qualifications had significantly higher scores than those with a degree on the domain relating to memory difficulties as obstacles to completing the FOBt (mean difference 0.329,  $p=0.007$ ).

The belief that screening would be pleasant was significantly lower for those with a degree compared to all other level of education groups: A level (mean difference 0.363,  $p=0.017$ ) G.C.S.E (mean difference 0.616,  $p=0.001$ ) and those with no formal qualifications (mean difference 0.654,  $p<0.001$ ). Furthermore, those with a degree rated the importance of regular bowel function in order to complete the FOBt as lower than those with no formal qualifications (mean difference 0.531,  $p<0.001$ ).

Some differences across domains and beliefs by level of education, mainly between those with a degree and those with no formal qualifications, were found to be marginally non-significant. These are italicised in table 6.16. Those with a degree had lower scores on the ‘Beliefs about Consequences’ domain than those with no formal qualifications, where the latter group’s higher scores denoted greater perceived benefits of taking part in CRC screening (mean difference 0.251,  $p=0.049$ ). Perceived risk was also marginally higher for those with no formal qualifications than those with a degree (mean difference 0.251,  $p=0.049$ ). Furthermore, those with no formal qualifications also thought it was better to complete the FOBt than provide a (stool) sample in a pot compared to those with a degree (mean difference 0.135,  $p=0.037$ ). Lastly, for the item regarding the need to complete the FOBt at home, there were no significant post hoc differences between the education groups.

**Table 6.15:** Level of education by TDF and psychological variables

Psychological variables	Mean (S.D) by Level of education (n=505)				ANOVA		
	No formal qualifications	G.C.S.E/ O Level	A Level or equivalent	Degree or higher	F	P value	$\eta^2$
<i>Perceived risk</i>	3.27 (0.90)	3.20 (0.78)	3.16 (0.83)	3.02 (0.73)	2.604	0.051	0.015
<b>Screening would be pleasant</b>	<b>3.24 (1.07)</b>	<b>3.20 (1.10)</b>	<b>2.95 (1.04)</b>	<b>2.59 (1.13)</b>	<b>10.584</b>	<b>&lt;0.001</b>	<b>0.060</b>
Anticipated regret	4.52 (0.96)	4.47 (0.82)	4.59 (0.75)	4.55 (0.82)	0.314	0.815	0.002
Early detection leads to successful treatment	4.36 (0.76)	4.25 (0.66)	4.38 (0.62)	4.28 (0.68)	0.862	0.461	0.005
<i>Would need to complete FOBt at home</i>	4.09 (0.93)	3.78 (1.15)	3.77 (1.13)	3.78 (1.09)	2.492	0.059	0.015
Relief at normal result	4.64 (0.66)	4.61 (0.53)	4.67 (0.67)	4.61 (0.61)	0.254	0.858	0.002
Bowel cancer is fatal	4.40 (0.74)	4.29 (0.72)	4.50 (0.63)	4.51 (0.69)	2.109	0.098	0.012
Important to keep healthy	4.61 (0.72)	4.53 (0.63)	4.60 (0.75)	4.70 (0.53)	1.414	0.238	0.008
<b>Would need regular bowel function to complete FOBt</b>	<b>3.39 (1.15)</b>	<b>3.22 (1.16)</b>	<b>3.13 (1.16)</b>	<b>2.86 (1.08)</b>	<b>5.663</b>	<b>0.001</b>	<b>0.033</b>
Bowel cancer is a hidden disease	4.14 (0.78)	4.07 (0.67)	4.08 (0.90)	4.13 (0.73)	0.212	0.888	0.001
Religious beliefs would not impact my taking part in screening	4.32 (1.10)	4.36 (0.66)	4.33 (1.05)	4.50 (0.82)	1.223	0.301	0.007
Important to look after self for family	4.54 (0.71)	4.54 (0.57)	4.54 (0.74)	4.43 (0.69)	0.929	0.426	0.006
<i>FOBt would better than sample in a pot</i>	3.95 (0.89)	3.81 (1.04)	3.79 (0.98)	3.63 (0.98)	2.607	0.051	0.015

	Mean (S.D) by Level of education (n=505)				ANOVA		
	No formal qualifications	G.C.S.E/ O Level	A Level or equivalent	Degree or higher	F	P value	$\eta^2$
<b>Psychological variables</b>							
Would be inappropriate to discuss bowel cancer screening with others	1.87 (0.96)	1.92 (0.84)	1.87 (0.95)	1.76 (0.81)	0.767	0.513	0.005
People close to me would approve of me completing the FOBt	4.45 (0.73)	4.25 (0.71)	4.33 (0.84)	4.33 (0.68)	1.081	0.357	0.006
Religious beliefs say no to bowel cancer screening	1.47 (0.61)	1.51 (0.57)	1.50 (0.73)	1.43 (0.63)	0.391	0.759	0.002
Beliefs about Capabilities	4.36 (0.62)	4.32 (0.62)	4.39 (0.53)	4.33 (0.59)	0.325	0.807	0.002
Emotions	2.28 (0.64)	2.28 (0.66)	2.33 (0.67)	2.33 (0.66)	0.176	0.913	0.001
<b>Knowledge</b>	<b>3.40 (0.81)</b>	<b>3.22 (0.75)</b>	<b>3.07 (0.82)</b>	<b>2.86 (0.81)</b>	<b>11.211</b>	<b>&gt;0.001</b>	<b>0.063</b>
Practical Barriers (environmental context)	1.66 (0.65)	1.62 (0.65)	1.57 (0.61)	1.50 (0.56)	1.941	0.122	0.011
<i>Beliefs about Consequences</i>	<i>4.52 (0.53)</i>	<i>4.47 (0.40)</i>	<i>4.56 (0.42)</i>	<i>4.42 (0.50)</i>	<i>2.529</i>	<i>0.057</i>	<i>0.015</i>
<b>Social and Religious Influence</b>	<b>3.24 (0.81)</b>	<b>3.04 (0.76)</b>	<b>3.14 (0.79)</b>	<b>2.84 (0.79)</b>	<b>7.310</b>	<b>&gt;0.001</b>	<b>0.042</b>
<b>Memory, Attention &amp; Decision</b>	<b>2.89 (0.80)</b>	<b>2.66 (0.81)</b>	<b>2.71 (0.87)</b>	<b>2.56 (0.88)</b>	<b>3.621</b>	<b>0.013</b>	<b>0.021</b>
<b>Conceptual Knowledge</b>	<b>1.90 (0.92)</b>	<b>2.20 (0.83)</b>	<b>2.09 (0.87)</b>	<b>2.30 (0.76)</b>	<b>5.722</b>	<b>0.001</b>	<b>0.033</b>
Behavioural regulation	4.29 (0.68)	4.32 (0.50)	4.37 (0.55)	4.38 (0.51)	0.722	0.539	0.004

### **6.3.7ii.c IMD quintile**

Fewer differences in domains and beliefs were found across participants' IMD quintiles as shown in table 6.16. Those who resided in the most deprived 20% areas rated CRC screening as more pleasant than those who resided in the third most deprived 20% areas (mean difference 0.576,  $p=0.001$ ) and those who resided in the least deprived 40% areas (mean difference 0.814,  $p=0.012$ ).

With regards to requiring regular bowel function in order to complete the FOBt, those in the most deprived 20% areas had significantly higher scores than those who resided in the third most deprived 20% areas (mean difference 0.447,  $p=0.023$ ). However, those who resided in the third most deprived 20% areas had significantly higher scores on the same item than those who resided in the least deprived 40% areas (mean difference 0.810,  $p=0.035$ ).

For the item that stipulated it was important to look after one's self for their family's sake, people living in the most deprived 20% areas had significantly higher scores than those who resided in the least deprived 40% areas (mean difference 0.424,  $p=0.001$ ).

Differences in 'Knowledge' about CRC and the screening programme were also found where those living in the second most deprived 20% areas had lower level of knowledge than those living in the most deprived 20% areas (mean difference 0.237,  $p=0.022$ ). No differences in knowledge were found between the remaining IMD quintile groups.

The final domain to vary by IMD quintile was the 'Social and Religious Beliefs' domain. People living in the most deprived 20% areas had higher scores than those living in the second most deprived 20% areas (mean difference 0.213,  $p=0.041$ ), indicating greater impact of social and religious factors on health motivation and beliefs about screening.

**Table 6.16:** *IMD quintile by TDF and psychological variables*

Psychological variables	Mean (S.D) by IMD quintile (n=506)				ANOVA		
	20% Most deprived	2	3	40% least deprived	F	P value	$\eta^2$
Perceived risk	3.15 (0.83)	3.13 (0.84)	3.11 (0.77)	3.11 (0.57)	0.080	0.971	0.001
<b>Screening would be pleasant</b>	<b>3.13 (1.11)</b>	<b>2.87 (1.08)</b>	<b>2.55 (1.18)</b>	<b>2.32 (0.89)</b>	<b>7.382</b>	<b>&lt;0.001</b>	<b>0.042</b>
Anticipated regret	4.45 (0.92)	4.62 (0.78)	4.57 (0.76)	4.79 (0.42)	2.065	0.104	0.012
Early detection leads to successful treatment	4.37 (0.66)	4.31 (0.69)	4.26 (0.72)	4.21 (0.63)	0.728	0.536	0.004
Would need to complete FOBt at home	3.83 (1.03)	3.83 (1.10)	3.89 (1.14)	3.95 (1.18)	0.129	0.943	0.001
Relief at normal result	4.61 (0.66)	4.63 (0.64)	4.68 (0.58)	4.74 (0.45)	0.387	0.762	0.002
Bowel cancer is fatal	4.44 (0.69)	4.45 (0.70)	4.49 (0.65)	4.58 (0.77)	0.300	0.825	0.002
Important to keep healthy	4.57 (0.76)	4.7 (0.50)	4.59 (0.70)	4.84 (0.38)	2.101	0.099	0.012
<b>Would need regular bowel function to complete FOBt</b>	<b>3.16 (1.16)</b>	<b>3.11 (1.13)</b>	<b>2.72 (1.13)</b>	<b>3.53 (0.96)</b>	<b>3.888</b>	<b>0.009</b>	<b>0.023</b>
BC is a hidden disease	4.04 (0.86)	4.14 (0.72)	4.22 (0.71)	4.32 (0.75)	1.584	0.192	0.009
Religious beliefs would not impact my taking part in screening	4.33 (0.99)	4.49 (0.82)	4.3 (1.12)	4.47 (1.02)	1.424	0.235	0.008
<b>Important to look after self for family</b>	<b>4.42 (0.77)</b>	<b>4.52 (0.66)</b>	<b>4.61 (0.59)</b>	<b>4.84 (0.38)</b>	<b>3.153</b>	<b>0.025</b>	<b>0.018</b>
FOBt would better than sample in a pot	3.68 (1.07)	3.79 (0.92)	3.95 (0.79)	4 (0.88)	1.821	0.142	0.011

	Mean (S.D) by IMD quintile (n=506)				ANOVA		
	20% Most deprived	2	3	40% least deprived	F	P value	$\eta^2$
<b>Psychological variables</b>							
Would be inappropriate to discuss bowel cancer screening with others	1.89 (0.89)	1.73 (0.82)	1.92 (1.06)	1.95 (0.78)	1.561	0.198	0.009
People close to me would approve of me completing the FOBt	4.31 (0.79)	4.38 (0.68)	4.36 (0.82)	4.42 (0.61)	0.356	0.785	0.002
Religious beliefs say no to bowel cancer screening	1.51 (0.68)	1.41 (0.61)	1.50 (0.67)	1.47 (0.61)	0.931	0.426	0.006
Beliefs about Capabilities	4.38 (0.56)	4.37 (0.54)	4.24 (0.63)	4.36 (0.57)	1.162	0.324	0.007
Emotions	2.31 (0.67)	2.27 (0.59)	2.42 (0.77)	2.33 (0.59)	1.004	0.391	0.006
<b>Knowledge</b>	<b>3.22 (0.80)</b>	<b>2.98 (0.84)</b>	<b>3.03 (0.88)</b>	<b>2.96 (0.76)</b>	<b>3.155</b>	<b>0.025</b>	<b>0.019</b>
Practical Barriers (environmental context)	1.62 (0.62)	1.52 (0.53)	1.62 (0.76)	1.37 (0.46)	1.950	0.121	0.012
Beliefs about Consequences	4.50 (0.47)	4.48 (0.48)	4.46 (0.51)	4.46 (0.41)	0.142	0.935	0.001
<b>Social and Religious Influence</b>	<b>3.16 (0.83)</b>	<b>2.95 (0.79)</b>	<b>2.91 (0.80)</b>	<b>2.95 (0.51)</b>	<b>3.223</b>	<b>0.022</b>	<b>0.019</b>
Memory, Attention & Decision	2.78 (0.79)	2.62 (0.89)	2.55 (0.89)	2.92 (0.99)	2.478	0.061	0.015
Conceptual Knowledge	2.07 (0.86)	2.15 (0.84)	2.22 (0.90)	2.37 (0.68)	1.079	0.357	0.006
Behavioural regulation	4.31 (0.61)	4.37 (0.54)	4.43 (0.47)	4.45 (0.44)	1.124	0.339	0.007



### 7.3.7iii Variation of psychological beliefs by ethnicity and SES

A series of 4 (ethnicity) x 3 (SES, measured through social deprivation; SD), factorial ANOVAs were conducted to examine the main effects of ethnicity and SES for TDF domains and individual items. Effect sizes were generally very small for the few statistically significant differences that were detected.

A significant main effect of ethnicity on intentions to complete the FOBt was found ( $F(3,466)=3.347$ ,  $p=0.019$ , partial  $\eta^2=0.021$ ) however, there was no significant main effect of SD on intentions ( $F(2,466)=0.321$ ,  $p=0.726$ , partial  $\eta^2=0.001$ ). There was also a non-significant ethnicity by SD interaction ( $F(6,466)=0.525$ ,  $p=0.790$ , partial  $\eta^2=0.007$ ). In relation to Beliefs about Capabilities, there were no significant main effects of either ethnicity ( $F(3,466)=1.867$ ,  $p=0.134$ , partial  $\eta^2=0.012$ ), SD ( $F(2,466)=0.607$ ,  $p=0.545$ , partial  $\eta^2=0.003$ ) and a non-significant ethnicity by SD interaction ( $F(6,466)=0.842$ ,  $p=0.538$ , partial  $\eta^2=0.011$ ). Similarly, regarding 'Emotions', there were no significant main effects of ethnicity ( $F(3,466)=2.083$ ,  $p=0.102$ , partial  $\eta^2=0.013$ ) or SD ( $F(2,466)=0.019$ ,  $p=0.981$ , partial  $\eta^2=0.001$ ), as well as a non-significant ethnicity by SD interaction ( $F(6,466)=1.325$ ,  $p=0.244$ , partial  $\eta^2=0.017$ ). Furthermore, there were no significant main effects on the 'Practical barriers' domain for ethnicity ( $F(3,466)=1.204$ ,  $p=0.308$ , partial  $\eta^2=0.008$ ), SD ( $F(2,466)=1.841$ ,  $p=0.160$ , partial  $\eta^2=0.008$ ) and a non-significant ethnicity by SD interaction ( $F(6,466)=0.882$ ,  $p=0.508$ , partial  $\eta^2=0.011$ ).

For the 'Social role and identity domain', there was a marginally non-significant main effect of ethnicity ( $F(3,466)=2.441$ ,  $p=0.064$ , partial  $\eta^2=0.015$ ). There was also a non-significant main effect of SD on the 'Social role and identity domain' ( $F(2,466)=1.982$ ,  $p=0.139$ , partial  $\eta^2=0.008$ ), as well as a non-significant ethnicity by SD interaction ( $F(6,466)=0.623$ ,  $p=0.712$ , partial  $\eta^2=0.008$ ). In relation to 'Memory, attention and decision domain', again

there were no significant main effects of ethnicity ( $F(3,466)=0.818$ ,  $p=0.484$ , partial  $\eta^2=0.005$ ) or SD ( $F(2,466)=1.952$ ,  $p=0.143$ , partial  $\eta^2=0.008$ ) as well as a non-significant ethnicity by SD interaction ( $F(6,466)=0.015$ ,  $p=0.298$ , partial  $\eta^2=0.015$ ).

For the 'Beliefs about Consequences' domain, there were no main effects of ethnicity ( $F(3,466)=0.437$ ,  $p=0.727$ , partial  $\eta^2=0.003$ ) or SD ( $F(2,466)=1.558$ ,  $p=0.212$ , partial  $\eta^2=0.007$ ) but there was a significant ethnicity by SD interaction ( $F(6,466)=2.32$ ,  $p=0.032$ , partial  $\eta^2=0.029$ ). The nature of this interaction was examined by calculating the simple main effects of SD for each ethnic group, indicating that for Black Caribbean participants, those in the least deprived SD 0 category had significantly higher scores (mean=4.75, s.d.=0.33) than those in the intermediate SD 1 category (mean=4.20, s.d.=0.58); ( $F(2,466)=3.242$ ,  $p=0.040$ , partial  $\eta^2=0.014$ ), while the mean scores of the three other ethnic groups did not vary by level of SD.

In relation to 'Knowledge' of CRC and the screening programme, there was a significant main effect of ethnicity ( $F(3,466)=6.040$ ,  $p<0.001$ , partial  $\eta^2=0.037$ ) and SD ( $F(2,466)=6.23$ ,  $p=0.002$ , partial  $\eta^2=0.026$ ). Sidak corrected pairwise comparisons indicated that the knowledge of Black Caribbean participants was higher than the knowledge of White British participants (mean difference 0.556,  $p=0.002$ ). For SD, the knowledge of participants in the highest social deprivation SD 2 category was significantly lower than participants in both the intermediate SD 1 category (mean difference 0.695,  $p=0.002$ ) and those in the lowest SD 0 category (0.827,  $p=0.014$ ). However, there was no significant ethnicity by SD interaction for knowledge, possibly due to small cell counts ( $F(6,466)=0.626$ ,  $p=0.421$ , partial  $\eta^2=0.013$ ). For 'Conceptual knowledge' about CRC screening, there was no significant main effect of ethnicity ( $F(2,466)=1.936$ ,  $p=0.123$ , partial  $\eta^2=0.012$ ), but there was a significant effect of SD ( $F(2,466)=4.441$ ,  $p=0.012$ , partial  $\eta^2=0.019$ ). Examination of the Sidak corrected pairwise comparisons showed that the conceptual knowledge of the most

deprived SD 2 group was significantly lower than both the intermediate SD 1 (mean difference 0.585,  $p=0.018$ ) and the least deprived SD 0 groups (0.783,  $p=0.029$ ). In addition, the ethnicity by SD interaction was non-significant ( $F(6,466)=1.238$ ,  $p=0.286$ , partial  $\eta^2=0.016$ ).

For 'Behavioural regulation', there was a significant main effect of ethnicity ( $F(3,466)=6.537$ ,  $p<0.001$ , partial  $\eta^2=0.040$ ) but no significant main effect for SD ( $F(2,466)=2.258$ ,  $p=0.106$ , partial  $\eta^2=0.010$ ). Black Caribbean (BC) and White British (WB) participants had significantly higher scores on the behavioural regulation domain than White Other participants (BC mean difference 0.465,  $p=0.039$  and WB mean difference 0.606,  $p<0.001$ ). There was also a significant ethnicity by SD interaction ( $F(6,466)=3.220$ ,  $p=0.004$ , partial  $\eta^2=0.040$ ). Simple main effects of SD for each ethnic group were calculated to examine the nature of this interaction, indicating firstly that Black Caribbean participants in the least deprived SD 0 group had significantly greater behavioural regulation scores than those in the intermediate SD 1 and most deprived SD 2 groups ( $F(2,466)=3.804$ ,  $p=0.023$ , partial  $\eta^2=0.016$ ). Similarly, White Other participants in the least deprived SD 0 group also had significantly higher behavioural regulation than both the SD 1 and SD 2 groups ( $F(2,466)=5.443$ ,  $p=0.005$ , partial  $\eta^2=0.023$ ). No ethnicity by SD differences in behavioural regulation were found for White British and Black African groups.

Examination of the single items showed that for perceived risk, there were no significant effects of ethnicity ( $F(3,466)=1.675$ ,  $p=0.172$ , partial  $\eta^2=0.011$ ) or SD ( $F(2,466)=1.502$ ,  $p=0.224$ , partial  $\eta^2=0.006$ ), or their interaction ( $F(6,466)=p=$ , partial  $\eta^2=0.023$ ). However, for perceived pleasantness of screening, there were significant main effects of both ethnicity ( $F(3,466)=3.961$ ,  $p=0.008$ , partial  $\eta^2=0.025$ ) and SD ( $F(2,466)=5.130$ ,  $p=0.006$ , partial  $\eta^2=0.022$ ), as well as a marginally non-significant ethnicity by SD interaction ( $F(6,466)=1.918$ ,  $p=0.076$ , partial  $\eta^2=0.024$ ). Pairwise comparisons indicated that White

British participants rated screening as significantly less pleasant than Black Caribbean participants (mean difference 0.610,  $p=0.016$ ). For SD, the least deprived SD 0 group had significantly lower pleasantness ratings than both the SD 1 group (mean difference 0.749,  $p=0.042$ ) and the most deprived SD 2 group (mean difference 1.229,  $p=0.005$ ). Examination of the simple main effects of the ethnicity by SD interaction illustrated that White British participants in the least deprived SD 0 category had significantly lower scores on the perceived pleasantness of CRC screening than people of the same ethnicity in more deprived categories, SD 1 and SD 2 ( $F(2,466)=8.682$ ,  $p<0.001$ , partial  $\eta^2=0.036$ ). For Black Caribbean participants, those in the most deprived SD 2 category had significantly higher perceived pleasantness scores than people in the intermediate SD 1 category ( $F(2,466)=4.353$ ,  $p=0.013$ , partial  $\eta^2=0.018$ ). The final difference for this item was for White Other participants, where those in the most deprived SD 2 category had significantly higher perceived pleasantness scores than those in the least deprived SD 0 category ( $F(2,466)=4.747$ ,  $p=0.009$ , partial  $\eta^2=0.020$ ).

A similar pattern to that described above was evident for anticipated regret where there were significant main effects of both ethnicity ( $F(3,466)=3.232$ ,  $p=0.022$ , partial  $\eta^2=0.020$ ) and SD ( $F(2,466)=4.865$ ,  $p=0.008$ , partial  $\eta^2=0.020$ ), alongside a significant ethnicity by SD interaction ( $F(6,466)=3.140$ ,  $p=0.005$ , partial  $\eta^2=0.039$ ). Pairwise comparisons showed that anticipated regret was higher for White British participants than Black African participants only (mean difference 0.979,  $p=0.014$ ). In relation to SD, the most deprived SD 2 group had marginally lower anticipated regret than the SD 1 (mean difference 0.477,  $p=0.066$ ) and significantly higher anticipated regret than the SD 0 group (mean difference 0.913,  $p=0.007$ ). Analysis of the simple main effects comprising the ethnicity by SD interaction showed that Black African participants in the most deprived SD 2 group had significantly lower levels of anticipated regret than those in the less deprived SD 1 and SD 0 groups ( $F(2,466)=9.081$ ,  $p<0.001$ , partial  $\eta^2=0.038$ ). No ethnicity by SD effects were apparent for

Black Caribbean, White Other and White British participants in relation to anticipated regret.

For the item that stipulated that early detection of CRC would lead to successful treatment, there were no significant effects of ethnicity ( $F(3,466)=1.302$ ,  $p=0.273$ , partial  $\eta^2=0.008$ ) or SD ( $F(2,466)=2.402$ ,  $p=2.402$ ,  $0.092$ , partial  $\eta^2=0.010$ ) or their interaction ( $F(6,466)=2.058$ ,  $p=0.057$ , partial  $\eta^2=0.026$ ). Likewise, there were no significant effects of ethnicity ( $F(3,466)=0.761$ ,  $p=0.516$ , partial  $\eta^2=0.005$ ) or SD ( $F(2,466)=1.338$ ,  $p=0.263$ , partial  $\eta^2=0.006$ ), or their interaction ( $F(6,466)=1.625$ ,  $p=0.138$ , partial  $\eta^2=0.020$ ) for the item that stated one would feel relieved getting a normal result. In addition, there were no significant effects of ethnicity ( $F(3,466)=0.525$ ,  $p=0.665$ , partial  $\eta^2=0.003$ ), SD ( $F(2,466)=1.071$ ,  $p=0.344$ , partial  $\eta^2=0.005$ ) or their interaction ( $F(6,466)=0.628$ ,  $p=0.708$ , partial  $\eta^2=0.008$ ) on the item that stipulated CRC is a hidden a disease. However, for the item that stipulated that CRC is fatal, there was no significant effect of ethnicity ( $F(3,466)=0.921$ ,  $p=0.430$ , partial  $\eta^2=0.006$ ), but there was a significant main effect of SD ( $F(2,466)=4.225$ ,  $p=0.015$ , partial  $\eta^2=0.018$ ) as well as a significant ethnicity by SD interaction ( $F(6,466)=3.496$ ,  $p=0.002$ , partial  $\eta^2=0.043$ ). Exploration of this interaction revealed that Black Caribbean participants in the intermediate SD 1 group (mean=3.86, s.d.=0.73) were significantly less likely to think that CRC is a fatal disease than those in the least deprived SD 0 group (mean=4.83, s.d.=0.41); ( $F(2,466)=5.677$ ,  $p=0.004$ , partial  $\eta^2=0.024$ ). However, SD did not appear to make a difference to the scores of Black African, White Other or White British participants' scores on this item.

For the item relating to a general motivation to look after one's health, there were no significant effects of ethnicity ( $F(3,466)=0.069$ ,  $p=0.976$ , partial  $\eta^2=0.001$ ), SD ( $F(2,466)=1.010$ ,  $p=0.365$ , partial  $\eta^2=0.004$ ), or their interaction ( $F(6,466)=1.544$ ,  $p=0.162$ , partial  $\eta^2=0.019$ ). Similarly, there were no significant effects of ethnicity ( $F(3,466)=0.767$ ,

$p=0.513$ , partial  $\eta^2=0.005$ ), SES ( $F(2,466)=0.415$ ,  $p=0.660$ , partial  $\eta^2=0.002$ ) or their interaction ( $F(6,466)=0.012$ ) on the item that reflected family as a reason to look after one's health.

In relation to factors regarding the completion of the FOBt, for the item that stated one would need to complete the FOBt at home, there were no significant effects of either ethnicity ( $F(3,466)=0.768$ ,  $p=0.513$ , partial  $\eta^2=0.005$ ), SD ( $F(2,466)=0.514$ ,  $p=0.598$ , partial  $\eta^2=0.002$ ) or their interaction ( $F(6,466)=1.275$ ,  $p=0.598$ , partial  $\eta^2=0.016$ ). Moreover, with regards to the item that said completing the FOBt would be preferable to providing a sample in a pot, there were also no significant effects of ethnicity ( $F(3,466)=1.389$ ,  $p=0.245$ , partial  $\eta^2=0.009$ ), SD ( $F(2,466)=2.204$ ,  $p=0.112$ , partial  $\eta^2=0.009$ ) or their interaction ( $F(6,466)=0.574$ ,  $p=0.751$ , partial  $\eta^2=0.007$ ). For the item relating to the need for regular bowel function in order to complete the FOBt, there was no significant effect of ethnicity ( $F(3,466)=1.139$ ,  $p=0.333$ , partial  $\eta^2=0.007$ ) though there was a significant main effect of SD ( $F(2,466)=3.260$ ,  $p=0.039$ , partial  $\eta^2=0.014$ ) where pairwise comparisons showed that those in the most deprived SD 2 category endorsed this view to a greater extent than those in the least deprived SD 0 group (mean difference 1.036,  $p=0.041$ ). However, there was no significant ethnicity by SD interaction for this item ( $F(6,466)=0.710$ ,  $p=0.642$ , partial  $\eta^2=0.009$ ).

For the item stating one's religious beliefs would not impact decisions to take part in screening or not, there were no significant effect of ethnicity ( $F(3,466)=0.929$ ,  $p=0.426$ , partial  $\eta^2=0.006$ ), SD ( $F(2,466)=0.989$ ,  $p=0.373$ , partial  $\eta^2=0.004$ ) or their interaction ( $F(6,466)=0.388$ ,  $p=0.887$ , partial  $\eta^2=0.005$ ). However, for a similar item that specified one's religious beliefs would stop one from taking part in screening, a significant main effect of ethnicity was found ( $F(3,466)=3.199$ ,  $p=0.023$ , partial  $\eta^2=0.020$ ). Pairwise comparisons showed that the difference was greatest between White British and Black African

participants, where the latter group's higher scores denoted greater religious influence (mean difference 0.726,  $p=0.028$ ). There was no significant main effect of SD with regards to this item ( $F(2,466)=0.787$ ,  $p=0.456$ , partial  $\eta^2=0.003$ ) or a significant ethnicity by SD interaction ( $F(6,466)=1.645$ ,  $p=0.456$ , partial  $\eta^2=0.021$ ).

With regards to an item related to aspects of social influence, the belief that significant others would approve of one taking part in screening, there were no significant effects of ethnicity ( $F(3,466)=2.028$ ,  $p=0.109$ , partial  $\eta^2=0.013$ ), SD ( $F(2,466)=0.038$ ,  $p=0.963$ , partial  $\eta^2=0.001$ ) or their interaction ( $F(6,466)=0.219$ ,  $p=0.971$ , partial  $\eta^2=0.003$ ). However, another social influence related belief that stated the discussion of CRC screening with others would be inappropriate, there was a significant main effect of ethnicity ( $F(3,466)=6.462$ ,  $p<0.001$ , partial  $\eta^2=0.040$ ) and SD ( $F(2,466)=4.327$ ,  $p=0.014$ , partial  $\eta^2=0.018$ ) as well as a significant ethnicity by SD interaction ( $F(6,466)=3.406$ ,  $p=0.003$ , partial  $\eta^2=0.042$ ). Black African participants more strongly endorsed this view than White British (mean difference 1.398,  $p<0.001$ ), Black Caribbean (mean difference 1.415,  $p=0.001$ ) and White Other participants (mean difference 1.058,  $p=0.044$ ). For SD, the only difference was between the most deprived SD 2 group and the intermediate SD 1 group, where the former had higher scores on the item relating to the inappropriateness of discussing screening. Examination of the simple effects of the ethnicity by SD interaction indicated that Black Caribbean participants in the least deprived SD 0 category had significantly lower scores, indicating less importance of the approval of others, than Black Caribbean people in both the SD 1 and most deprived SD 2 category ( $F(2,466)=4.479$ ,  $p=0.012$ , partial  $\eta^2=0.019$ ). However, SD did not appear to influence the scores of Black African, White Other and White British participants' on this item.

### **6.3.8. Mediation analysis**

#### **6.3.8i Mediators of the impact of ethnicity screening intentions**

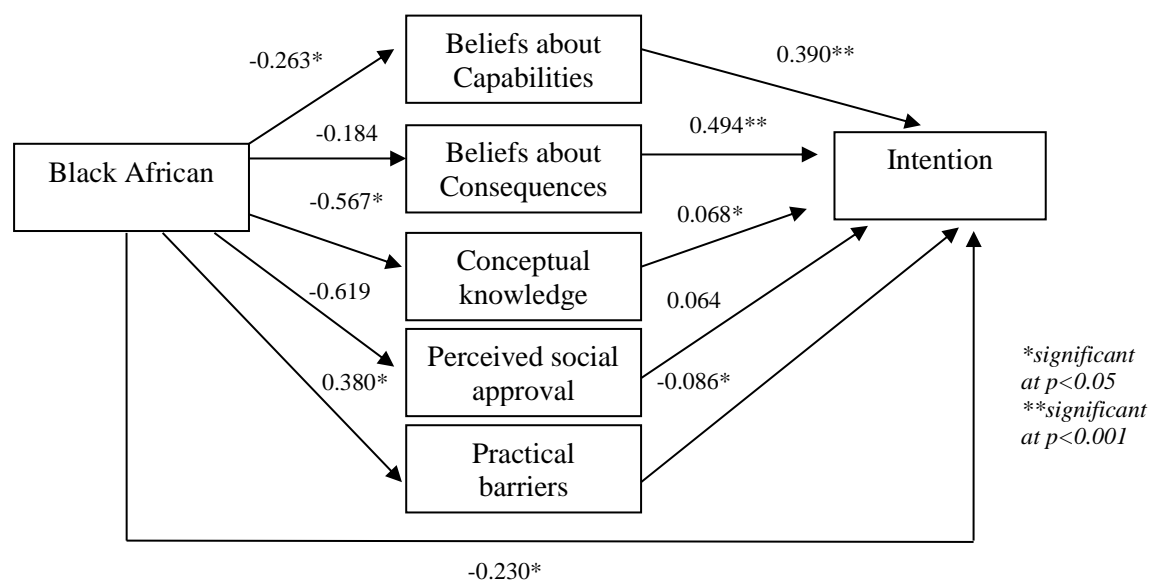
Multiple regression analyses in sections 6.3.3 and 6.3.4 showed that ethnicity as well as psychological factors including beliefs about capabilities, practical barriers, beliefs about consequences, conceptual knowledge and the perceived approval of screening by significant others, were all significant predictors of intentions for screening. Mediation analysis was conducted to examine whether the relationship between ethnicity and screening intention was mediated by the psychological factors outlined above. The results indicated that there was a significant direct effect of ethnicity on screening intentions ( $F(3,466)=3.759$ ,  $p=0.011$ ,  $R^2=0.013$ ). There were also a number of statistically significant specific indirect effects through all of the psychological variables, except the perceived approval of significant others, highlighted in bold in table 6.17, overleaf. Details of the coefficients between ethnicity, each of the proposed mediators and intentions are presented in figures 6.5, 6.6 and 6.7. All results are presented relative to White British participants who were the reference group in this analysis.

Relative to White British participants, the effect of being Black African on intentions was mediated by Black African people having lower beliefs about capabilities, conceptual knowledge and greater practical barriers. On the other hand, the effect of being Black Caribbean on intentions was only mediated by lower beliefs about consequences. For White Other participants, the effect of ethnicity on intentions was mediated by lower beliefs about capabilities only. Perceived approval of screening by significant others did not mediate any effect of ethnicity on intentions for screening.

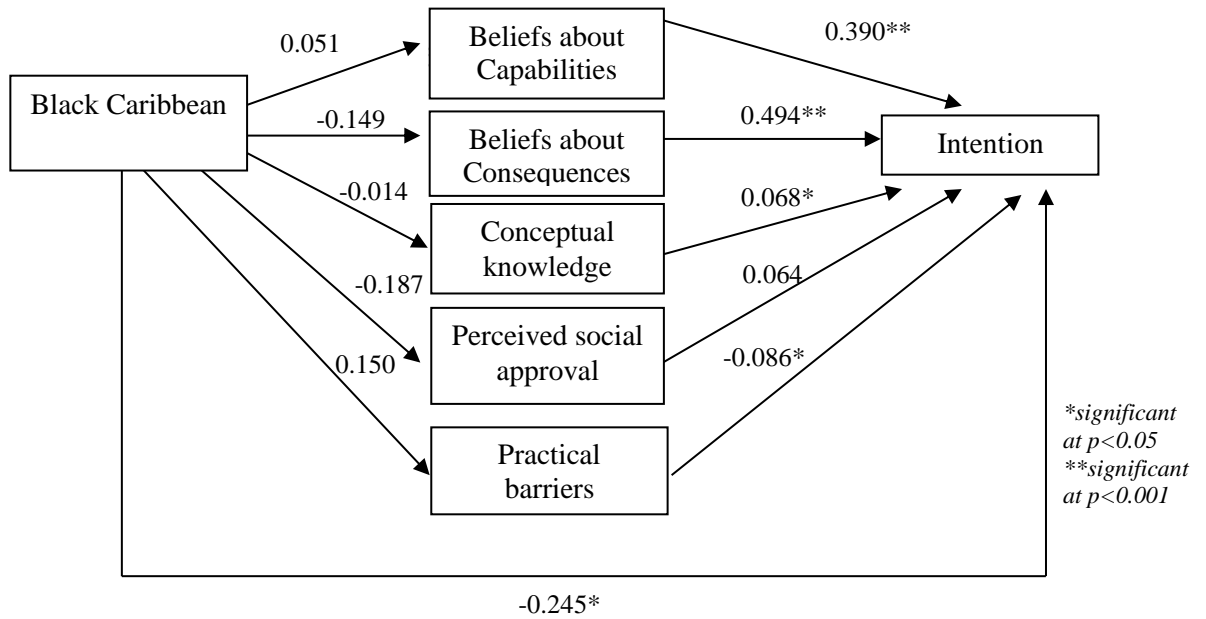


**Table 6.18:** Specific indirect effects of ethnicity on screening intentions, mediated by psychological factors

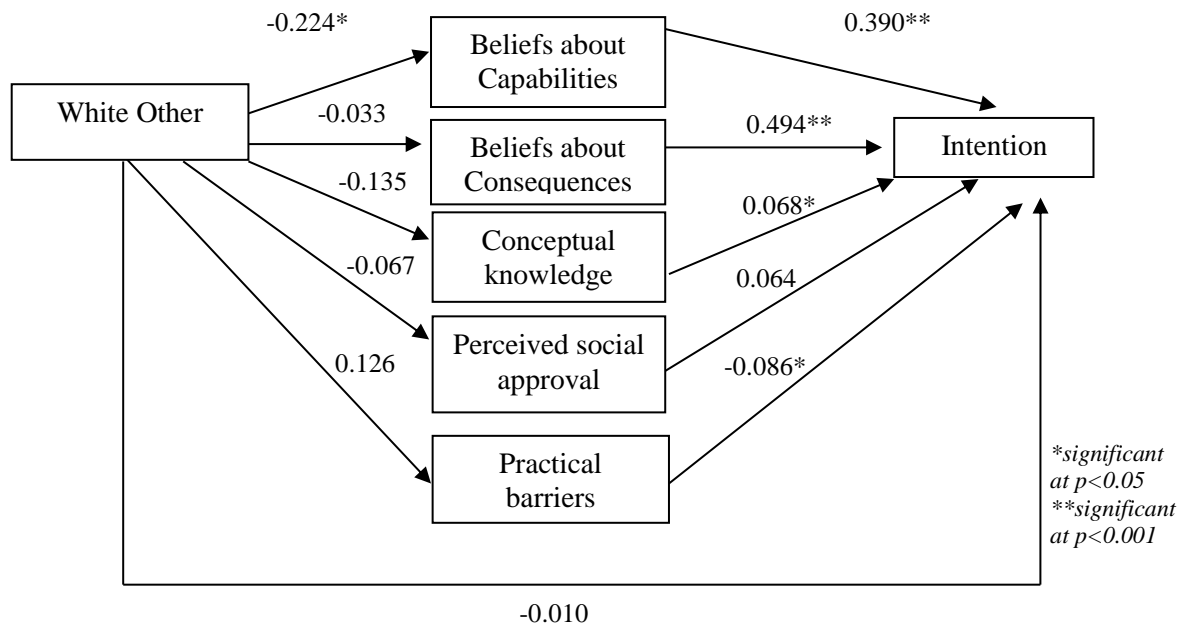
Psychological factor	Ethnicity	Point estimate	95 % Confidence Interval	
			Lower bound	Upper bound
Beliefs about Capabilities	<b>Black African</b>	<b>-0.127</b>	<b>-0.237</b>	<b>-0.016</b>
	Black Caribbean	-0.020	-0.092	0.041
	<b>White Other</b>	<b>-0.087</b>	<b>-0.208</b>	<b>-0.016</b>
Beliefs about consequences	Black African	-0.091	-0.267	0.010
	<b>Black Caribbean</b>	<b>-0.074</b>	<b>-0.190</b>	<b>-0.001</b>
	White Other	-0.016	-0.091	0.045
Conceptual knowledge	<b>Black African</b>	<b>-0.039</b>	<b>-0.086</b>	<b>-0.008</b>
	Black Caribbean	-0.001	-0.024	0.017
	White Other	-0.009	-0.036	0.004
Perceived approval of significant others	Black African	-0.039	-0.117	0.000
	Black Caribbean	-0.012	-0.046	0.002
	White Other	-0.004	-0.032	0.005
Practical barriers	<b>Black African</b>	<b>-0.033</b>	<b>-0.110</b>	<b>-0.001</b>
	Black Caribbean	-0.013	-0.061	0.002
	White Other	-0.011	-0.053	0.001



**Figure 6.5:** Path analysis examining the relationship between Black African ethnicity, psychological factors and screening intentions, relative to White British participants.



**Figure 6.6:** Path analysis examining the relationship between Black Caribbean ethnicity, psychological factors and screening intentions, relative to White British participants



**Figure 6.7:** Path analysis examining the relationship between White Other ethnicity, psychological factors and screening intentions, relative to White British participants.

### **6.3.8.ii Mediators of screening uptake**

Findings from the logistic regressions that were undertaken to determine the demographic and psychological predictors of screening uptake revealed that ethnicity was a significant predictor alongside screening intentions and behavioural regulation. Whether or not intentions and behavioural regulation mediated the effect of ethnicity on uptake was examined in further mediation analysis. As the model contained a dichotomous outcome variable (uptake: yes/no) as well as a categorical independent variable (ethnicity), three separate mediation analyses were undertaken using dummy codes for ethnicity as recommended by Hayes, (2012). The results presented below thus reflect the indirect effects for each ethnic group (Black African, Black Caribbean and White British), relative to White British participants, who were the reference group, while controlling for the existence of the other ethnic groups.

Results of the mediation analysis showed that there was a significant direct effect of ethnicity on screening uptake for Black Caribbean and White Other participants, but not for Black African participants. Furthermore, intentions and behavioural regulation significantly mediated the impact of Black African and Black Caribbean ethnicity on screening uptake where intentions and behavioural regulation were significantly lower for both groups than for White British participants. For White Other participants, the significant indirect effect on screening uptake was through behavioural regulation only which was significantly lower than White British participants. Tables 6.19, 6.20 and 6.21 overleaf display the direct, total and specific indirect effects of each ethnic group on screening uptake, mediated by behavioural regulation and intentions. Figures 6.8, 6.9 and 6.10 illustrate the path analysis for each ethnic group.

**Table 6.19:** Direct, total and specific indirect effects of Black African ethnicity (relative to White British ethnicity) on screening uptake, mediated by psychological variables

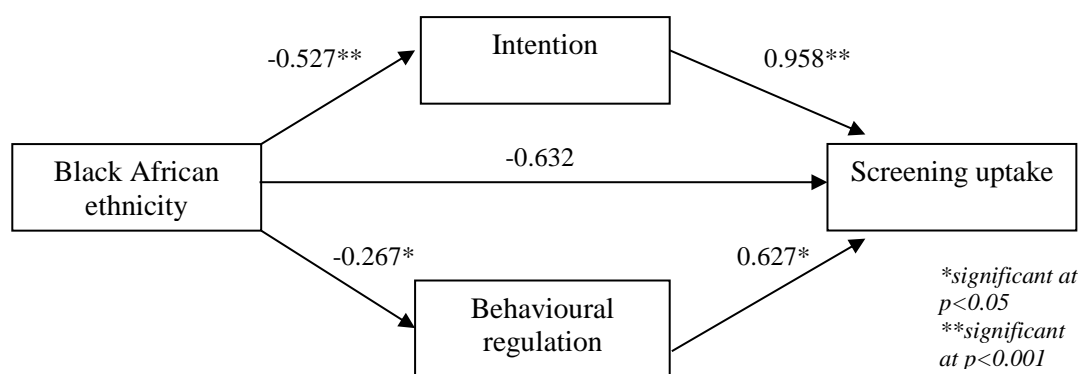
	Point estimate	P value	95 % Confidence Interval	
			Lower bound	Upper bound
<b>Direct effect</b>	-0.632	0.136	-1.462	0.198
<b>Indirect effect</b>				
Total	-0.673		-1.143	-0.319
Intention	-0.505		-0.911	-0.215
Behavioural regulation	-0.168		-0.412	-0.041

**Table 6.20:** Direct, total and specific indirect effects of Black Caribbean ethnicity (relative to White British ethnicity) on screening uptake, mediated by psychological variables

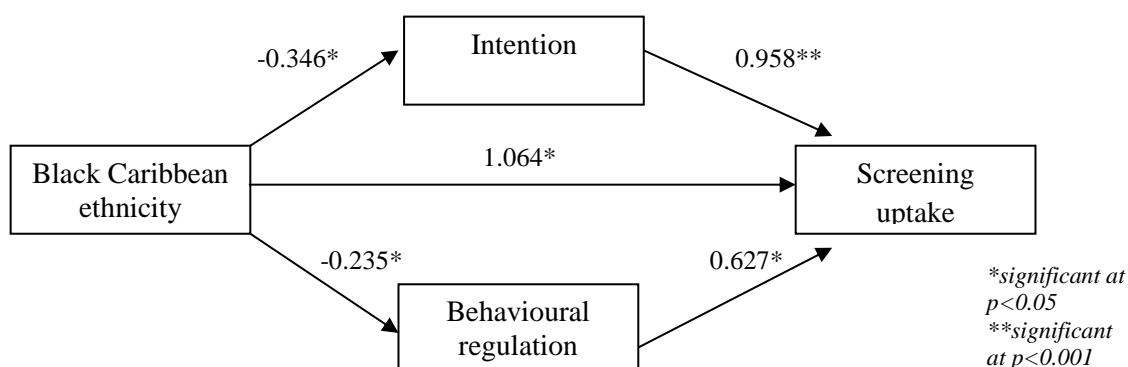
	Point estimate	P value	95 % Confidence Interval	
			Lower bound	Upper bound
<b>Direct effect</b>	1.064	0.033	0.087	2.042
<b>Indirect effect</b>				
Total	-0.479		-0.798	-0.247
Intention	-0.332		-0.585	-0.170
Behavioural regulation	-0.147		-0.405	-0.033

**Table 6.21:** Direct, total and specific indirect effects of White Other ethnicity (relative to White British ethnicity) on screening uptake, mediated by psychological variables

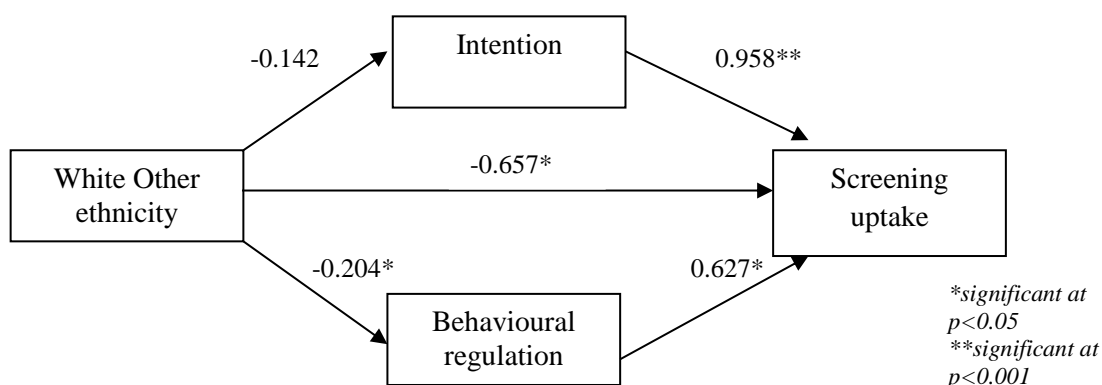
	Point estimate	P value	95 % Confidence Interval	
			Lower bound	Upper bound
<b>Direct effect</b>	-0.657	0.046	-1.303	-0.010
<b>Indirect effect</b>				
Total	-0.264		-0.635	-0.009
Intention	-0.136		-0.427	0.051
Behavioural regulation	-0.128		-0.327	-0.011



**Figure 6.8:** Path analysis examining the relationship between Black African ethnicity, psychological factors and screening uptake, relative to the White British group



**Figure 6.9:** Path analysis examining the relationship between Black Caribbean ethnicity, psychological factors and screening uptake, relative to the White British group



**Figure 6.10:** Path analysis examining the relationship between White Other ethnicity, psychological factors and screening uptake, relative to the White British group

### 6.3.9 Demographic predictors of informed choice

Overall 385 (75.9%) participants were found to have made an uninformed choice and 122 (24.1%) participants made an informed choice about participating in screening or not. Seventy percent of participants (n=355) held a positive attitude towards CRC screening, with the remaining 30% holding negative attitudes (n=152). In terms of conceptual knowledge about CRC and screening, 61.7% of participants (n=313) had “poor knowledge” and 38.3% (n=194) had “good knowledge”. Table 6.22, below, displays the extent of attitude/value, knowledge and behaviour consistency that underpinned informed and uninformed choices made by participants in this study. As shown in the table, poor knowledge was a reason for uninformed choices to take part in screening for just over a third of all participants. When knowledge was poor and values and behaviour were also inconsistent, uninformed choices about screening participation were made by just over 20% of participants. However, when knowledge was good, inconsistency between participants’ values and behaviour appeared to underpin uninformed choices for a relatively small proportion of participants (4.72% of those who had not been screened and 8.48% of those had been screened).

**Table 6.22:** *Extent of attitude, knowledge and behaviour consistency in informed and uninformed choices*

	Knowledge	Attitude	Uptake	No. of participants (%)
<b>Informed choices</b>	Good	Positive	Screened	108 (21.30%)
	Good	Negative	Not screened	14 (2.67%)
<b>Informed, value-behaviour inconsistency</b>	Good	Positive	Not screened	29 (4.72%)
	Good	Negative	Screened	43 (8.48%)
<b>Poorly informed, values &amp; behaviour consistent</b>	Poor	Positive	Screened	167 (32.94%)
	Poor	Negative	Not screened	37 (7.30%)
<b>Poorly informed, values &amp; behaviour inconsistent</b>	Poor	Positive	Not screened	51 (10.06%)
	Poor	Negative	Screened	58 (11.44%)

Whether ethnicity and/or SES determined informed choice was examined through a series of logistic regressions. Each SES indicator: SD, level of education and IMD quintile were examined separately. Ethnicity was examined once independently and once alongside SD. As shown in table 6.23 below, for SES, SD and level of education were significant predictors of informed choice. Participants in the most deprived SD 2 and intermediate SD 1 groups were significantly less likely to make an informed choice than those in the least deprived SD 0 group. In relation to education, those educated to A level and above were significantly more likely to make an informed choice than those with no formal qualifications. The likelihood of making an informed choice did not differ for individuals educated to G.C.S.E/O level compared to those with no formal qualifications. IMD quintile was not a significant predictor of informed choice.

**Table 6.23:** *SES as a predictor of informed choice*

SES indicators	B	Wald $\chi^2$	P	Odds ratio	95% Confidence Intervals	
					Lower bound	Upper bound
SD*						
SD 1	-0.633	8.434	0.004	0.531	0.346	0.814
SD 2 (most deprived)	-1.019	5.495	0.019	0.361	0.154	0.846
Level of education^						
G.C.S.E/O level	0.329	0.637	0.425	1.390	0.619	3.122
A level	0.768	5.865	0.015	2.156	1.158	4.016
Degree and higher	0.726	5.709	0.017	2.067	1.139	3.748
IMD quintile†						
(2) Most deprived 20%	-0.258	0.190	0.663	0.772	0.242	2.468
(3) Most deprived 20%	0.023	0.002	0.966	1.023	0.352	2.979
Least deprived 40%	-0.217	0.158	0.691	0.805	0.276	2.347

\* SD reference category: SD 0 (least deprived)

^ Level of education reference category: no formal qualifications

† IMD quintile reference category: Most deprived 20%

With regards to ethnicity, when entered in the logistic regression alone, ethnicity was overall not a significant predictor of informed choice. However, there was a marginally non-significant result for the Black African group who were less likely to make an informed compared to White British participants. When the impact of ethnicity was examined alongside the SES indicator SD, only SD significantly predicted informed choice, where more deprived groups were less likely to make an informed choice than the least deprived group. The results are displayed in tables 6.24 and 6.25, below.

**Table 6.24:** *Ethnicity as a predictor of informed choice*

Ethnicity*	B	Wald $\chi^2$	P	Odds ratio	95% Confidence Intervals	
					Lower bound	Upper bound
Black African	-1.128	3.291	0.070	0.324	0.096	1.095
Black Caribbean	-0.354	0.735	0.391	0.702	0.312	1.577
White Other	-0.354	0.979	0.322	0.702	0.348	1.415

\* Note: White British participants were the reference group

**Table 6.25:** *Ethnicity and SES as a predictors of informed choice*

	B	Wald $\chi^2$	P	Odds ratio	95% Confidence Intervals	
					Lower bound	Upper bound
<b>Ethnicity*</b>						
Black African	-0.867	1.878	0.171	0.420	0.122	1.452
Black Caribbean	-0.084	0.038	0.845	0.920	0.396	2.134
White Other	-0.345	0.914	0.339	0.708	0.349	1.437
<b>SD<sup>†</sup></b>						
SD 1	-0.545	5.578	0.018	0.580	0.369	0.911
SD 2	-0.957	4.515	0.034	0.384	0.159	0.928

\*Reference group: White British

<sup>†</sup>SD reference category: SD 0 (least deprived)



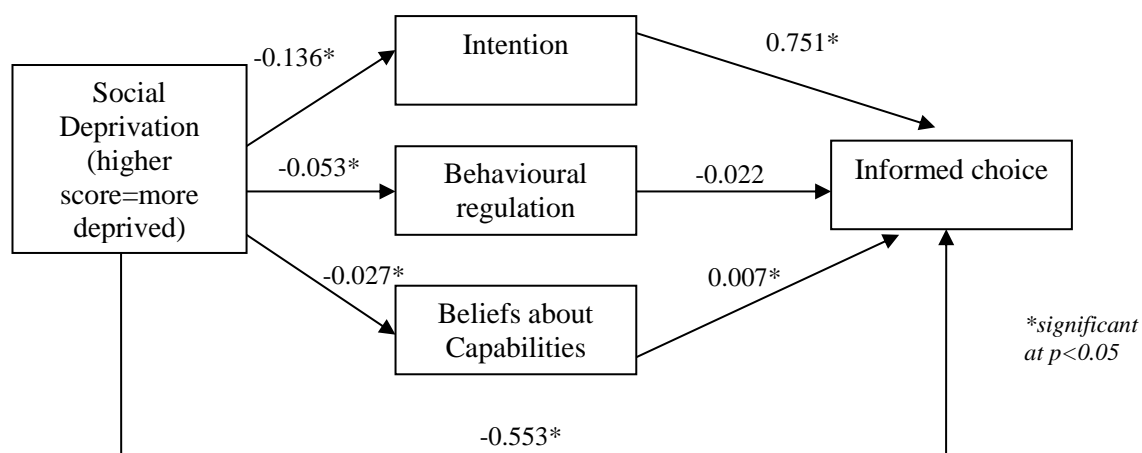
### 6.3.10 Mediators of the relationship between SES and informed choice

As intentions and behavioural regulation mediated the relationship between ethnicity and screening uptake, and beliefs about capabilities mediated the impact of ethnicity on intentions, all three variables were also included as possible mediators of the relationship between SES and informed choice.

In relation to the SES indicator Social Deprivation (SD), mediation analysis revealed that SD had a significant direct impact on informed choice, as well as an indirect effect through intention and beliefs about capabilities (see table 6.26 below). As level of deprivation increased, informed choice decreased. Likewise, when deprivation increased, participants' intentions for screening and beliefs about capabilities also decreased, which in turn led to a greater likelihood of an uninformed choice. Behavioural regulation did not mediate the effect of SD on informed choice. Figure 6.11, overleaf displays the path analysis of the relationship between SD and informed choice.

**Table 6.26:** Direct, total and specific indirect effects of SD on informed choice, mediated by psychological variables

	Point estimate	P value	95 % Confidence Interval	
			Lower bound	Upper bound
<b>Direct effect of SD</b>	-0.553	0.002	0.198	0.904
<b>Indirect effect</b>				
Total	0.101		0.012	0.249
Intention	-0.102		0.018	0.259
Behavioural regulation	-0.001		-0.319	0.031
Beliefs about Capabilities	0.002		0.221	0.029

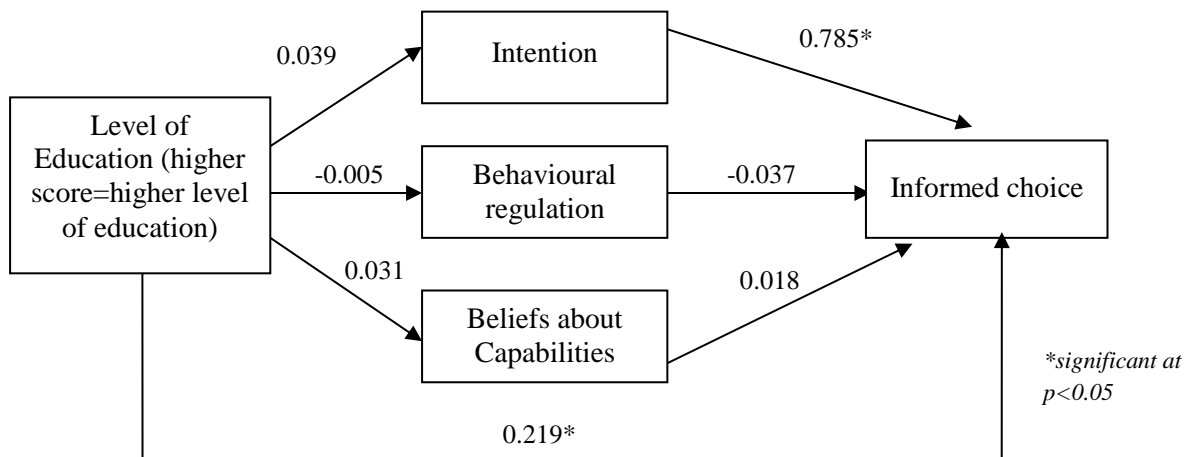


**Figure 6.11:** Path analysis examining the relationship between Social Deprivation and informed choice mediated by intention, behavioural regulation and beliefs about capabilities

When the relationship between level of education and informed choice was examined in mediation analysis, level of education had a significant direct impact on informed choice such that greater levels of education facilitated informed choice. Intentions, beliefs about capabilities and behavioural regulation did not appear to mediate the impact of level of education on informed choice. Table 6.27 below, displays the total, direct and indirect effects. Figure 6.12, overleaf, depicts the path analysis between level of education and informed choice through the proposed mediators.

**Table 6.27:** Direct, total and specific indirect effects of level of education on informed choice, mediated by psychological variables

	Point estimate	P value	95 % Confidence Interval	
			Lower bound	Upper bound
<b>Direct effect</b>	0.219	0.024	0.028	0.409
<b>Indirect effect</b>				
Total	0.029		-0.021	0.085
Intention	0.031		-0.010	0.095
Behavioural regulation	-0.001		-0.022	0.014
Beliefs about Capabilities	-0.000		-0.016	0.010



**Figure 6.12:** Path analysis examining the relationship between level of education and informed choice mediated by intention, behavioural regulation and beliefs about capabilities

## 6.4 Discussion

This study was designed to examine the psychological and socio-demographic factors, including ethnicity and socio-economic status, predictors of screening intentions and subsequent uptake of screening. A further aim of this study was to examine whether the uptake of screening was based on informed choice. This section will provide an overview of the main findings in the context of previous research, discuss the wider theoretical and practical implications of the results and finally, appraise the key strengths and limitations.

### 6.4.1 Summary of main findings

The results of this study indicate that intentions for and, participation, in CRC screening are underpinned by a combination of psychological and demographic factors. Multiple regression analysis indicated that intentions for screening were predicted by the demographic factor ethnicity, as well as a number of psychological theoretical domains including ‘beliefs about capabilities’, ‘beliefs about consequences’, ‘conceptual knowledge of CRC and screening’, ‘practical barriers’ and a belief concerning perceived approval of

screening participation by one's significant others. Analysis conducted to explore the underlying processes in the relationship between ethnicity and intentions indicated that psychological factors partly mediated this relationship but different factors were significant for different ethnic groups. For Black African participants, beliefs about capabilities', 'conceptual knowledge' and 'practical barriers' mediated the impact of ethnicity on intentions. For Black Caribbean participants however, the 'beliefs about consequences' domain was the only significant mediator between ethnicity whereas, only 'beliefs about capabilities' mediated screening intentions for White Other participants.

In relation to screening behaviour, significant predictors included ethnicity as well as intentions and behavioural regulation. Although past screening behaviour was also a significant predictor of uptake, the focus of this study was to identify the changeable psychological predictors of behaviour; thus the rationale for excluding past behaviour from further analysis was that it is unchangeable (McEachan, Conner et al. 2011). The findings of the mediation analysis showed that the relationship between ethnicity and screening uptake was mediated by intentions and behavioural regulation although the degree of mediation differed across ethnic groups. For Black African participants, there was no significant direct effect of ethnicity on screening uptake when compared to White British participants. Instead, intentions and behavioural regulation appeared to mediate the relationship between ethnicity and uptake. In other terms, lower uptake of screening for Black African participants reflected lower intentions and lower propensity for behavioural regulation, compared to White British participants. In contrast, ethnicity did have a direct effect on screening uptake for Black Caribbean and White Other participants, relative to White British participants. Black Caribbean participants were more likely to participate in screening than White British participants. Moreover, for Black Caribbean participants, the relationship between ethnicity and screening uptake was partially mediated by intentions and behavioural regulation. However, White Other participants were less likely to take part in screening than White

British participants and this effect was partially mediated by (lower levels of) behavioural regulation only.

With regards to informed choice, the findings of this study strongly indicate that whilst uptake of screening was overall quite high (~75%), it was not often based on informed choice. Inconsistencies in participants' values and knowledge were such that the majority of participants who made an uninformed choice to take part in screening, held positive attitudes but had poor knowledge. In addition, SES factors including social deprivation (SD) and level of education were significant predictors of informed choice. Those from more deprived backgrounds and those with lower educational attainment were less likely to make an informed choice about whether to participate in screening or not. When the pathways between these SES factors and informed choice were examined, (lower) intentions and (less strong) beliefs about capabilities partially mediated the negative impact of SD on informed choice. SD also had a significant direct effect on informed choice. In relation to level of education, again there was a significant direct effect where those with fewer educational qualifications (below A level) were less likely to make an informed choice. However, the effect of education on informed choice was not mediated by intentions, beliefs about capabilities and behavioural regulation. These findings will now be discussed in terms of previous research and theoretical understanding.

#### **6.4.2 Discussion of findings**

The finding that intentions and behavioural regulation were the main psychological predictors of screening uptake concur with the two main phases of behaviour outlined by Gollwitzer, (1993): motivational and volitional. In the motivational phase, individuals decide which goals to pursue and the volitional phase involves planning towards the fulfilment of these goals. Whilst theories of health behaviour and the majority of research have tended to focus on the motivational phase of behaviour, the importance of both motivational

(intentions) and volitional factors (behavioural regulation) for uptake of screening in this study lends further support for the inclusion of volitional factors. In terms of ethnic differences in screening uptake, the finding that Black Caribbean participants were more likely to participate concurs with the finding of high uptake for flexible sigmoidoscopy screening by “Black” participants (Robb, Power et al. 2008) alongside the reported high rates of screening attendance for cervical and breast cancer among Caribbean women (Sutton, Bickler et al. 1994).

Differences in screening uptake were not evident by SES captured by any of the different measures (SD, level of education and IMD quintile). This finding is contrary to previous research in UK based studies that have found a social gradient in the uptake of CRC screening, although the majority of studies focus on flexible sigmoidoscopy (Whynes, Frew et al. 2003, Wardle, McCaffery et al. 2004, Weller, Coleman et al. 2007, von Wagner, Baio et al. 2011). One possibility for the non-significant finding for SES may be that as the screening programme is now fully rolled out across England, previous differences in uptake found by SES may just have disappeared. As noted in the early chapters, as CRC screening is centrally organised difficulties accessing care are not paramount issues at the initial screening stage. However, there were fewer participants from low SES backgrounds in this study, as measured through individual level SES indicators education and social deprivation, which may be a more plausible explanation for the lack of significant findings. Furthermore, previous studies that have reported socio-economic variation in the uptake of CRC screening (Whynes et al., 2003, Weller et al., 2007, von Wagner et al., 2011) have used IMD scores which may incorrectly assume that individuals living in the same area share similar socio-economic characteristics (MacRae 1994, Morris, Baio et al. 2012). Thus, a replication of this study is recommended given the number of national and international studies have found SES differences in screening uptake.

Although differences in intentions of some ethnic groups were statistically significant, such as the lower intentions of Black African participants compared to White British participants, intentions for screening were overall high across all ethnic groups. This is consistent with findings from the FOBt pilots which found no differences between UK South Asian and non-South Asian groups in initial willingness to undergo screening (Szczepura, 2003a&b). Furthermore, these findings also concur with the work regarding flexible sigmoidoscopy where interest in screening was also quite high across different UK ethnic groups (Robb, Solarin et al. 2008). Consideration must be given to the role of the method of data collection as a possible reason for the relatively high intentions of participants in this study. The questionnaire was administered through a telephone interview which may have given rise to social pressure to give a desirable response and thus inadvertently inflating people's intentions of screening.

The findings of this study strongly alluded to the role of ethnicity in forming screening intentions. Moreover, contrary to research findings from USA that often portrays ethnic minority groups as disadvantaged and as holding more negative views about CRC screening, this was not the case for the minority groups in this study. For instance, knowledge and uptake of screening were higher for Black Caribbean participants. Moreover, Black Caribbean participants were less concerned about the approval of their significant others and were less pessimistic about CRC. Joint examination of the patterning of psychological beliefs, including the factors that were predictors of screening intentions, by ethnicity and SD as an indicator of SES identified many similarities across ethnic groups across several theoretical domains including 'beliefs about capabilities', 'beliefs about consequences', 'emotions', 'conceptual knowledge', 'practical barriers', 'memory, attention and decision' alongside 'social and religious influence'. Only intentions, 'knowledge' (self-reported) and behavioural regulation were found to differ across ethnic groups. Similarly for SD, the only significant differences were for self-reported 'knowledge' and 'conceptual knowledge', where more deprived groups had lower levels of both types of knowledge. In addition, some

interesting ethnicity by SD interactions were also apparent, although interpretation must be made with caution given the potentially small sub-groups. For instance, White British participants in the least deprived group perceived taking part in screening as less pleasant compared to people of the same ethnicity in more deprived groups. Conversely, Black Caribbean participants in the most deprived group were more likely to perceive taking part in screening as more pleasant than those in the intermediate SD group from the same ethnic background.

The overall uptake of screening for the participants in this study was high (74.2%). This is higher than the average for the SE London boroughs of Lambeth and Southwark (~40%) as well as the national of screening uptake average (~55%). Contrary to the rationale for undertaking the research presented in this thesis, the findings of this study would suggest that uptake of CRC screening is not “low” in this cohort of participants from SE London. One reason for this inconsistent finding could be that participating in this study, inadvertently had a positive impact on participants’ screening behaviour. Research has demonstrated a question-behaviour effect where merely asking questions about a behaviour may be sufficient to produce changes in the behaviour (Conner, Godin et al., 2011). Furthermore, the mode of data collection required interaction with a researcher who was able to answer any questions participants had about the screening programme or the FOBt, clear any misunderstandings as well as provide information. Indeed, some participants mentioned wanting to gain further information about the screening programme as motivation for participating in the survey.

### **6.4.3 Implications for psychological theory**

Consistent with several theoretical stances (Theory of Planned Behaviour; TPB, Health Belief Model; HBM, Social Cognitive Theory; SCT) and previous research, intention was the one of the main predictors of behaviour. The domain, ‘beliefs about consequences’,



similar to attitude, did not predict behaviour but was a strong predictor of intentions. Social influence, by way of the perceived approval of significant others influenced people's intentions to take part in screening, consistent with the TPB. However, emotions including fear of cancer and the outcome of screening (Geiger, Miedema et al. 2008, Austin, Power et al. 2009) as well as embarrassment (Brenes and Paskett 2000, Techer et al., 2009) and perceived risk (Chapple, Ziebland et al. 2008, Kim, Perez-Stable et al. 2008), Techer et al., 2009) that have been cited in previous research as important factors for CRC screening also did not play a part in predicting either intentions or behaviour.

Several social cognitive theories such as the theory of planned behaviour (Ajzen 1991) and social cognitive theory (Bandura 1986), as well as previous research have highlighted the role of factors such as self-efficacy or perceived behavioural control (PBC) in translating intentions into action. However, in the present study, beliefs about capabilities influenced people's intentions but not actual screening behaviour. Although self-efficacy was included as an item within the 'beliefs about capabilities domain, PBC was not included. Debates surrounding the independence/similarity of both constructs are not uncommon in the theoretical literature (Noar, Chabot et al. 2008) but it may be that the inclusion of a PBC measure in the questionnaire may have had different results. (Armitage and Conner 2001) found that PBC was a much weaker predictor of behaviour when behaviour was measured objectively than when it was measured through self-report, a finding that was replicated in a more recent meta-analysis by McEachan et al., (2011). Thus, another possible reason for the conflicting results of this study may be due to behaviour being measured objectively rather than through self-report, leading to the significance of different determinants.

As mentioned above, many theoretical constructs reported in previous studies did not influence intentions or screening uptake in this study. Questionnaire items were based on the salient beliefs of a small sub-set of the population of interest: participants of the qualitative study. It is possible that the beliefs of participants in the qualitative study were not salient for

participants in the questionnaire survey. Presenting participants with non-salient beliefs elevates the risk of them becoming salient as a result of measurement (Sutton, French et al. 2003, French and Sutton 2010). An alternative explanation for the non-significant findings for many of the TDF domains, stemming from the realms of social psychology, suggests that the explanations people give for their behaviour in a qualitative study may not accurately correspond to the factors that influence behaviour in action (Nisbett and Wilson 1977).

Interpretation of the findings in relation to the TDF may also be important. Whilst the TDF includes a broad range of theoretical constructs, perhaps too many related factors were simultaneously included in the questionnaire which resulted in extremely small effect sizes. This may be due to most of the variance in behaviour being accounted for by just two constructs: intentions and behavioural regulation. The role of intentions is consistent with prominent social cognitive theories such as the TPB, however behavioural regulation; the volitional aspect of behaviour, has been largely ignored by existing theories. To that end, inclusion of behavioural regulation is a particular strength of the TDF. Had the present study employed a different theoretical approach than the TDF, the importance of behavioural regulation in uptake of CRC screening, particularly for Black African, Black Caribbean and White Other participants, may have been missed. Nevertheless, there were some challenges of employing the TDF in this study. Firstly, the questionnaire required a lot of refinement due to initial low reliability of the domain sub-scales, resulting in a framework that had a very different structure to both the original and validated versions of the TDF (Michie et al., 2005, Cane et al., 2012). Furthermore, items that were supposedly theoretically related to same domain were separated in factor analysis e.g. perceived approval of significant others did not fit into the 'social and religious influence' domain alongside the belief regarding GP approval of screening. A further note regarding the TDF is that it is not a traditional theory that specifies the relationship between different domains which can be quantitatively examined and tested, thus restricting its explanatory value (Francis, Stockton et al. 2009).

#### **6.4.4 Strengths and limitations**

The low response rate to the mailed study invitation letter is a major shortcoming of this study despite the number of steps taken to encourage participation, such as gift vouchers as a token of gratitude. Although a low response rate of 20% was expected from previous studies using postal recruitment methods, the number of people who indicated they did not want to take part in the study was higher than expected. There are several potential shortcomings of the recruitment strategy. Firstly, the researcher could not approach participants personally to explain the aims in more detail, answer any queries they may have had or provide reassurance about the confidentiality of the study, as was the case with qualitative study where very few people declined participation. Secondly, a two stage recruitment strategy where individuals had to return a reply slip and then a convenient time for interview had to be scheduled was originally devised in recognition of the high social deprivation and potential literacy barriers that may be present in the areas the study was being conducted in. However, there were drawbacks to this approach as a number of individuals were uncontactable due to incorrect telephone numbers or were unable to schedule a convenient time for the interview. Furthermore, around 10% of letters sent were returned as undeliverable which reflects a further limitation in the postal method.

The overall sample included relatively small proportions of Black African and Black Caribbean participants who were the main ethnic groups of interest alongside White British participants. Had recruitment been targeted towards specific ethnic groups may have resulted in a more representative sample however, this was not possible due to the lack of ethnicity data in primary care databases that are used by the Screening Hub. Moreover, there were also smaller proportions of more socially deprived groups in the study which may partly explain the lack of significant findings regarding intentions and behaviour by SES. It is possible that fewer low SES groups participated in the study due to greater diversity in working patterns, including shift work. Although participants were given the option of

completing the questionnaire by post, they were required to have made some contact with the researcher by returning the reply slip or by telephone. It is possible that those who did not respond to study invitations may have had difficulties reading the study information sheet or could not complete the telephone interview due to long work patterns. Essentially, the unequal sample sizes may have contributed to the findings of the statistical analysis by either emphasising differences between ethnic and SES groups when they were in fact trivial or conversely, masking differences when they were significant. A post hoc power calculation indicated that the number of Black African, Black Caribbean and White British participants accrued still yielded 80% power to detect differences in screening uptake. The post hoc power calculation was undertaken following realisation that the original power calculation had been based on detecting differences between two groups: White British and Non-White, which the discussion in chapter two indicated may not be an appropriate strategy.

Offering an incentive by way of gift vouchers to participants did not help attain a representative sample and there may have been a response bias where ethnic minority groups and those from more deprived backgrounds were less likely to respond to study invitations. According to Hussain-Gambles, Atkin et al., (2004), under-representation in health research studies of ethnic minority groups, deemed as “hard to reach”, may be caused by a mixture of the particular requirements of groups, such as cultural or literacy needs, not being met, and some mistrust of the healthcare system. Therefore, greater refinement of recruitment strategies, beyond financial incentives may be required to engage socially and ethnically diverse participants in health research.

In addition to methodological limitations, the reliability of the questionnaire and individual domains may have contributed to the findings given the lack of correspondence in structure with published versions of the TDF and low internal reliability of some scales (Michie et al., 2005, Cane et al., 2012). Although internal reliability can be a useful check of the quality of

the data, it may be of limited utility to evaluate aspects of validity, particularly construct validity. Furthermore, high alpha values of internal reliability may indicate excessive narrowness of a scale and underestimate reliability if it is multi-dimensional (McCrae, Kurtz et al., 2011), as was the case in this study.

Regarding the measure of informed choice, based on the recommendation of Marteau et al., (2001), a median split was used to divide participants with good and poor knowledge, and those with positive and negative attitudes. However, as the median for the attitudes scale was high (median=4.5) this meant that those holding a positive attitude (scoring 4.5 on a 5 point scale) were thus deemed as holding a negative attitude. Likewise for knowledge, those scoring above 2 (on a 4 point scale) were deemed as having good knowledge. Thus, it is possible that those who were uninformed may have been classed as informed and vice versa. Future work may consider more satisfactory ways of distinguishing those with positive and negative attitudes apart from the median split (Hewison and Bryant 2009).

A further potential limitation is regarding the risk of type 1 error or the risk of inflated relationships when in reality, they may be non-significant. In this study, the criterion for statistical significance was set at 0.05 due to the exploratory nature of the research. However, due to the multiple statistical comparisons undertaken, it is possible that using this significance level may have increased the risk of type 1 error.

Despite the limitations discussed above, this is the first study in the UK to examine the intentions and behaviour regarding CRC screening via FOBt, with consideration of psychological, ethnicity and socio-economic factors. Furthermore, the study also contributes to the body of research about the factors that affect uptake of screening in ethnically and socio-economically diverse areas of London. Research to date has included very few prospective studies and the adoption of a prospective design in this study enabled the potentially causal influences on intentions and behaviour to be examined. Therefore, the

present study was able to identify the factors that predicted behaviour and mediation analysis helped provide some explanation of the underlying mechanisms driving behaviour.

#### **6.4.5 Conclusion**

Whilst the influence of psychological, ethnic and socio-economic factors on screening uptake has been extensively studied, few prospective studies have examined all three types of factors together and used mediation analysis to explore potential mechanisms. The findings of this study have identified some important determinants of screening intentions and behaviour, with some variation by ethnicity. More importantly, the findings demonstrated that uptake of CRC screening was not low for all ethnic minority groups, as indicated by previous research. This reinforces the need for studies that are designed to explore ethnic differences to refrain from combining all non-white groups for analysis, and also examine ethnic group differences in the context of socio-economic factors. However, high uptake was reflected by considerable lower rates of informed choice. Understanding of the determinants of behaviour is the first step. The next step is to identify theory based behaviour change techniques to target the determinants. Some potential intervention strategies to facilitate informed choices in screening decisions will be outlined in the next and, final chapter.

## Chapter Seven

### Thesis Conclusions and Future Directions

#### 7.1. Chapter Overview

The aims of this thesis were to explore the reasons behind low uptake of CRC screening in South East London and examine the possible impact of psychological factors. This final chapter appraises the extent to which the aims of this thesis were met along with a discussion of the implications of the results of the conducted studies. The chapter is divided in two parts: the first part presents a summary of the findings in relation to the research questions presented in chapter one alongside a discussion of the strengths and limitations of the thesis. The second part of the chapter reflects on the theoretical framework that underpinned the research with some implications for the facilitation of informed choices. This is followed by a discussion of possible intervention strategies and future research directions.

#### Part 1: Summary of the research presented in this thesis

*Research question 1: What are the beliefs about CRC screening of the main ethnic groups of these areas – African, Caribbean and White British people, and are there any differences between groups after considering socio-economic factors?*

Qualitative and quantitative methods (chapters five and six, respectively) were used to explore the beliefs about CRC screening of Black African, Black Caribbean, White British groups and White Other groups. Many similarities in beliefs were apparent across the ethnic groups. For instance, gaining peace of mind and reassurance from being screened were benefits of screening endorsed by all groups. The results of the qualitative study further

indicated that people of higher SES tended to be more confident about their ability to complete the FOBt and encountered fewer barriers than those of lower SES, regardless of ethnicity. However, some notable differences between ethnic groups were apparent, such as beliefs regarding the prevention of cancer by screening, civic responsibility to participate in screening for the benefit of others and faith in God, which were factors encouraging uptake for Black African and Black Caribbean groups. Furthermore, minority group participants were on the whole more accepting and positive about screening than White British participants.

The results of the questionnaire survey also highlighted some interesting similarities and differences in the views of the ethnic groups studied. When ethnicity was examined alone, beliefs about capabilities, emotions, knowledge, social and religious influence, perceived pleasantness of screening, anticipated regret and perceived risk were amongst the theoretical domains/beliefs that differed across ethnic groups. However, when considered alongside SES factors, many ethnic differences that were apparent in earlier analyses appeared to diminish. Only knowledge (self-reported) and behavioural regulation were found to differ by ethnicity. There were also some interesting ethnicity by SES interactions. For instance, White British participants in the least deprived group perceived completing the FOBt as significantly less pleasant than more deprived people from the same ethnic background. In contrast, Black Caribbean participants in the most deprived group perceived the FOBt to be significantly more pleasant than less deprived people from the same ethnic background. Reasons for these differences were unclear but suggest variation in the acceptability of screening and how it is valued by members of different ethnic and socio-economic groups. Nevertheless, perceived pleasantness did not predict screening intentions or behaviour. Referring back to the qualitative results, unlike White British participants, Black African and Black Caribbean participants were not concerned that the FOBt required collection of a faecal sample. Furthermore, some participants viewed collection of the faecal sample as a natural behaviour akin to practice in rural African areas where modern toileting facilities are



scarce. These findings suggest that culturally specific practices partly informed the beliefs of Black African and Black Caribbean participants, but overall, beliefs were similar across all ethnic groups once socio-economic factors were considered.

***Research question 2: Are low rates of CRC screening uptake in South East London underpinned by ethnicity, socioeconomic factors or do they represent informed choice?***

Chapter six indicated that uptake of CRC screening in South East London was influenced by a combination of ethnic and psychological factors. Although uptake of screening was relatively high across all participants, for the majority, uptake was not based on informed choice. Socio-economic factors, including three different SES indicators (individual level social deprivation, level of education and IMD quintile), did not appear to directly impact participation in screening but determined the extent to which people made an informed choice to participate in screening or not. Contrary to a wealth of research that indicates lower uptake of screening amongst some ethnic minority groups, participation in screening was greater for Black Caribbean participants than White British participants. However, uptake was still lower for Black African and White Other participants compared to White British participants. In terms of psychological factors, those who had weaker intentions to participate in screening and weaker behavioural regulation; being less certain that they would be able to plan when and where they would complete the FOBt and less certain that they could complete it independently, were less likely to participate in screening. Regarding informed choice, nearly a quarter of those who did not participate in screening had made an uninformed choice. Moreover, deficits in knowledge despite having positive attitudes towards screening was the most common reason for screening uptake being an uninformed choice where people who were more socially deprived in terms of educational attainment, car and home ownership, as well as those educated to secondary level or less, were less likely to make an informed choice. This relationship between SES and informed choice was partially mediated by intentions and beliefs about capabilities where people with higher

social deprivation had lower intentions and lower beliefs about capabilities, which led to lower rates of informed choice.

***Research question 3: Do psychological beliefs mediate the impact of demographic factors on screening uptake?***

Mediation analysis undertaken in chapter six helped identify some of the possible psychological mechanisms underpinning ethnic differences in screening uptake. For Black African participants, lower uptake of screening was mediated by lower intentions and lower behavioural regulation. However, psychological beliefs only partially mediated the effect of Black Caribbean and White Other ethnicity on screening uptake. The higher uptake of Black Caribbean participants was found to be partly due to stronger intentions and behavioural regulation whereas the lower uptake of screening for White Other participants was partially mediated by lower behavioural regulation only.

## **Strengths and Limitations of this thesis**

The strengths and limitations of each study were discussed following the presentation of the studies in each appropriate chapter (chapters four, five and six). In this section, the overall strengths and weaknesses of the thesis are considered.

There are three particular strengths of this thesis as a whole which enable it to make a distinct contribution to the field of health psychology and the understanding of screening from a public health perspective. The first strength relates to the structure of the thesis. Chapters two, three and four laid the foundations for understanding screening behaviour in different ethnic and SES groups. In chapter four, the TDF was used as the basis of interpretations of the narrative synthesis. In chapter five, a topic guide based on the TDF allowed the exploration of a range of motivational, social, cultural, environmental, emotional and volitional factors in relation to CRC screening. Salient beliefs arising from the

qualitative study were quantitatively examined in the questionnaire survey in chapter six. Thus, the use of a comprehensive psychological theoretical perspective, the TDF, was instrumental throughout this thesis. Finally, the thesis also allowed the exploration of informed choice and the extent to which this was evident in screening uptake by people in South East London.

Alongside psychological theory, the use of mixed methods to address the objectives is a further strength of this thesis. Although the use of mixed methods is not uncommon in health research, the results of qualitative and quantitative studies are often published separately (Moffatt, White et al. 2006). Furthermore, the way in which both methods are combined when interpreting data from particular studies is rarely documented (Moffatt et al., 2006). The integrated use of theory and methods not only provided evidence for the determinants of screening intentions and behaviour which could be targeted through intervention but also helped integrate the findings of the thesis as a whole.

A third strength of this thesis is the exploration of both ethnicity and socio-economic factors alongside psychological factors. Examination of both ethnic and socio-economic factors was particularly pertinent given the demographic profile of the area the research in this thesis was based. However, as demonstrated in the narrative synthesis in chapter four, many studies do not consider the influence of ethnicity and SES together, leading to biased/invalid conclusions about differences between ethnic groups which may in fact be underpinned by socio-economic factors. The tendency to not focus on both ethnicity and SES may be partly due to the complex relationship between the two, or a subtle interchangeable use of one for the other that was evident in North American studies. The studies in this thesis demonstrated that, contrary to previous research, ethnic minority participants did not always hold negative attitudes towards CRC screening and nor were they always less likely to take part in screening. However, a finding that was consistent with previous research was the lower knowledge about CRC and screening for both ethnic minority groups (Brouse et al., 2003,

Khan, 2010, Szczepura, 2003a, Waller, Robb et al. 2009) and those who were more socially deprived (Smith et al., 2010, McCaffery et al., 2003, Janda et al., 2002, Szczepura, 2003a, Techer et al., 2010, Schroy et al., 2008, Weinrich et al., 1992, O'Malley et al., 2004).

Although examining the impact of ethnicity in conjunction with socio-economic factors is a strength of this thesis, categorising people based on ethnicity is challenging - even when using 'standardised' definitions. As outlined in chapter 2, a multitude of factors influence people's perceptions of their own identity such as religion, country of birth and language. This is coupled with the multiple and interchangeable use of terms such as 'ethnicity', 'race' and 'culture', that in reality are quite separate constructs (Aspinall 2011). Furthermore, ethnic group options provided to participants may not always encompass the aspects individuals perceive to be part of their self-identity.

Considering the subjective nature of ethnicity, individuals asked to report their ethnicity will naturally draw on different aspects, in ways which are relevant to them, and the importance of the different aspects of ethnicity will also vary between groups. Despite the measurement of ethnicity being complex, it is crucial to deciphering health inequalities amongst particular groups as well as assessing the risk of discrimination (Aspinall 2011). However, more crucial is the reliable and contextually appropriate measurement of ethnicity in health research as emphasised by the haphazard measurement of ethnicity in studies reviewed in chapter four.

A number of limitations of this thesis also warrant attention. The first potential limitation regards the generalisability of the findings due to the relatively small numbers of ethnic minority groups recruited in the questionnaire survey. As ethnicity information is not yet a routine part of patient information held by the NHS, recruitment of participants could not be targeted towards specific ethnic groups. Furthermore, there were also considerably fewer participants from more socially deprived backgrounds despite the considerable steps that

were taken to facilitate participation from more socially deprived participants, such as telephone interviews to mitigate literacy barriers. Future research will need to utilise more specialist and refined techniques to recruit larger proportions of people from ethnic minority and socially deprived backgrounds. Previous studies employing population survey methods such as *Ethnibus* to examine beliefs regarding CRC screening via flexible sigmoidoscopy have yielded relatively large sample sizes (Robb, Power et al. 2008, Robb, Solarin et al. 2008) but require considerable financial resources to implement. The more personal, GP practice based recruitment strategy employed in the qualitative study was also successful in accruing a range of ethnically and socially diverse participants, but may be more time consuming for a study requiring several hundred participants. However, a learning point from employing this strategy in the qualitative study was the potential exclusion of people who do not regularly engage with primary care services and may also be less likely to engage in screening.

One methodological limitation that is relevant to most studies applying social cognition models is that intentions, when assessed by questionnaire, are simply a proxy measure of an actual decision (Bish, Sutton et al. 2000, Sutton, 2004). Individuals' decisions to participate in CRC screening might be made after receiving an invitation letter (in the questionnaire study, this was up to two months after completing the proxy measure of intention), or they could be made upon receipt of the FOBt a week or so after the initial screening invitation. Studies applying social cognition models assume that an individual has already made the decision or makes it when they complete the questionnaire. However, intentions are also prone to change after measurement (Bish et al., 2000). People may receive new information or have discussed screening participation with someone and therefore their intentions may change. It would be possible (although limited to being a post hoc justification) to ask people about their reasons for their behaviour after the event in order to clarify this as some studies have done (Szczepura 2003b). More often, there may be other unforeseen practical barriers that prevent intentions being translated into behaviour. For example, participants in

the qualitative study who were unable to complete the FOBt cited barriers such as kits being spoilt prior to completion or simply not “getting round to it”. This latter reason is consistent with the findings of previous research regarding cervical screening (Waller, Bartoszek et al. 2009).

Although mediation analysis undertaken in the questionnaire survey alluded to some of the psychological mechanisms that operated between ethnicity and screening uptake, there remains a need to experimentally test whether manipulating these beliefs does result in behaviour change. The next section will present some potential intervention strategies with equal focus on motivational and volitional aspects of behaviour.

## **Part 2: Thesis reflections and implications**

### **Intervention strategies**

The importance of interventions being based on theory is well documented within the literature. To develop our scientific understanding of the principles of behaviour change, it is important to have clear and agreed standards for identifying the ‘active ingredients’ and for designing, evaluating and reporting interventions (Michie and Johnston 2012). As well as the importance of using theory to inform the design of interventions, it is integral to specify the component ‘behaviour change techniques’ (BCTs; *ibid*). BCTs refer to the observable, replicable and irreducible components of an intervention that target the processes regulating behaviour (Michie, Johnston et al. 2013). The utilisation of BCTs in interventions can enable researchers to identify the techniques that are effective for changing particular behaviours. Recently, Michie et al., (2013) developed a hierarchical taxonomy of 93 distinct BCTs that could be applied to a wide range of behaviours. However, the majority of the BCTs within this taxonomy and similar previous taxonomies focus on interventions that are designed to change the behaviour of individuals (Michie et al., 2013). Thus, it is presently unclear how

these individual level strategies can be extended to the community and population level that may be relevant to the present thesis. Moreover, research to date has identified effective BCTs to improve a range of health behaviours including physical activity and healthy eating (Michie, Abraham et al. 2009), and smoking cessation (Michie, Hyder et al. 2011), but no research has examined the BCTs that would be effective for enabling screening participation. This issue will be discussed later in relation to informed choice.

Research has also emerged linking BCTs with determinants of behaviour such as those included in the TDF (Michie, Johnston et al. 2008). The two psychological determinants of screening behaviour identified in the questionnaire survey were intentions and behavioural regulation. According to consensus methodology utilised by Michie et al., (2008), where multiple health psychology researchers assigned specific BCTs to the domains of the TDF, BCTs appropriate for changing intentions that fall within the ‘motivation and goals’ domain would include a) specification of a goal or intention, b) a contract to complete the behaviour, c) offering a reward or incentive to complete the behaviour, d) increasing skills in problem solving, decision-making and goal-setting, e) social support and encouragement, f) persuasive communication from a credible source, g) information about the behaviour and outcome and h) motivational interviewing. Techniques that were deemed appropriate to improve behavioural regulation included a) specification of a goal or intention, b) a contract to complete the behaviour, c) planning each step of the behaviour, d) the use of prompts or triggers and e) the use of planned visual, sensory or motor images such as mental rehearsal. It is noteworthy to highlight that the selection of these BCTs is based on expert opinion which are influenced by people’s experience and knowledge thus further research on the effectiveness of these techniques for each relevant theoretical domain is still required. Furthermore, as apparent in the description above, some BCTs such as a contract to complete behaviour were considered to be relevant to changing both intentions and behavioural regulation thus further operationalisation of techniques would be useful in

determining for which aspects of intentions and behavioural regulation the techniques would be effective.

In light of the potentially relevant BCTs for CRC screening behaviour discussed above, the content of published intervention studies focusing on CRC screening also warrants attention. A recent systematic review by Brouwers, De Vito et al. (2011) evaluated RCT studies, conducted between 2004 and 2010, that were designed to increase uptake of CRC screening as well as breast and cervical cancer screening. Sixty six studies yielding 74 comparisons were included in the review where intervention effectiveness was determined by calculating the overall median post-intervention increase in completed screening tests. Successful strategies to increase CRC screening uptake included the use of screening reminders in via either printed letters or telephone calls, small media including videos, the distribution of tailored or untailored printed materials such as letters, brochures, pamphlets, flyers and newsletters by healthcare systems or community groups, reducing structural barriers such as problems with transportation or scheduling of appointments (for clinic based procedures e.g. colonoscopy) or language barriers, and finally healthcare provider (HCP) audit and feedback which involved the evaluation of how HCPs offered or delivered screening to their patients and providing HCPs with feedback on their performance. However, caution is required when interpreting the findings from this review as the majority of studies were based in the USA where screening remains opportunistic and requires people to either pay or be reimbursed from their health insurance provider, thus limiting the relevance of these results to the UK context. Furthermore, American studies tended to feature multiple screening tests for CRC including FOBt, flexible sigmoidoscopy and colonoscopy with some inconsistent results across effective intervention strategies for the same screening test. It would be useful for future research to explore effective intervention strategies for individual screening tests especially given that the implementation of flexible sigmoidoscopy screening alongside FOBt is imminent in the UK. Furthermore, in the studies reviewed by Brouwers et al., (2011), there appeared to be an inherent lack of consistency in the specification of BCTs in



interventions. For instance, both letters and invitations, which can be classed as modes of administering/delivering an intervention, were implicated as strategies rather than the corresponding BCT; providing information about the possible outcomes of performing the behaviour (through a written letter) (Michie et al., 2008). Moreover, with regards to the mechanisms driving behaviour change, studies rarely discussed intervention strategies in relation to their theoretical underpinnings (Brouwers et al., 2011). Although studies in the review by Brouwers et al., (2011) included intervention strategies that were appeared to be based on theory, the lack of theoretical integration of strategies with determinants of behaviour seriously limits the utility of the findings in terms of identification of the ‘active ingredients’ of interventions. Thus, there appears a divide in research recommendations and intervention research in practice.

Going back to the determinants of screening behaviour, the central tenet of many social cognitive models advocates intentions as the proximal determinants of behaviour and this was a finding in the questionnaire study. However, both previous research and the findings from this thesis suggest that intention is not always sufficient in order to perform behaviour. For instance, in a meta-analysis of interventions changing intentions, Webb and Sheeran (2006) found that a “medium-to-large” change in intention ( $d=.66$ ) would incur a “small-to-medium” change in behaviour ( $d=.36$ ). Furthermore, the majority of participants in the questionnaire survey had high intentions to participate in screening but not all of these participants carried them out. The findings also indicated the role of another important determinant of behaviour – behavioural regulation that relates to the planning and execution of behaviour. More specifically, as a post intentional factor, behavioural regulation refers to the active steps people take to translate their intention into behaviour (Michie et al., 2005). The next section will focus on behavioural regulation and volitional strategies that may enable individuals who want to complete the FOBt to do so.

## **Volitional strategies**

Action planning, which refers to specifying when, where and how to perform a behaviour (Gollwitzer 1999) and coping planning, which specifies how to deal with anticipated barriers (Sniehotta, Schwarzer et al. 2005) are two behaviour change techniques that focus on helping motivated individuals to bridge the gap between their intention and behaviour. Action plans differ from coping plans in their function in that the former are used to facilitate actions and the latter to limit distractions (Sniehotta 2009). In relation to completing the FOBt, there may be a number of levels of planning that may be required such as:

1. planning how to collect the sample and how to apply it to the kit
2. planning when one will complete the FOBt amongst other daily activities such as work
3. planning where one will complete the FOBt (e.g. at home or at work)
4. planning how and where to store the FOBt kit for subsequent samples (e.g. in bathroom cabinet)
5. any dietary planning to ensure bowels open regularly

In addition, a number of coping planning strategies may be required to overcome potential barriers such as concerns about smell, hygiene and disgust as well any mobility/vision problems where one may require help completing the FOBt. The use of action and coping plans in screening programmes whose aim is to provide informed choice may be limited by the need to ensure that instructions to form plans are targeted only at those who want to have the test (Michie, Dormandy et al. 2004). Although health related interventions which include planning components can be easily delivered through email, phone calls or phone applications, additional considerations may be required for more socially deprived groups (Michie et al., 2004).

Research applying action planning interventions have required participants to form implementation intentions to specify when (e.g. time of day and day of week) and where (e.g. disabled toilet at work) they will undertake a behaviour (Gollwitzer, 1993). Interventions utilising implementation intentions have demonstrated desirable changes in behaviour such as increasing fruit and vegetable intake (Kellar and Abraham 2005) and reducing saturated fat intake (Prestwich, Ayres et al. 2008), but not for screening uptake (Michie et al., 2004). In an experimental study designed to increase uptake of antenatal screening in women who were intending to undergo screening, Michie et al., (2004) found there was no difference in screening attendance rates between women who made an action plan/implementation intention and those in the control group. However, women in the intervention group who made an action plan were more likely to undergo screening than other women in the intervention group who did not make an action plan and this difference remained significant after controlling for demographic variation. There are a number of issues that require consideration when interpreting these findings in relation to this thesis. Firstly, the study population predominantly included women who were from more socially-economically deprived backgrounds whereas other research studies typically include more highly educated, student samples who may be more motivated to comply with study objectives. Moreover, the target behaviour in this study was objectively assessed while other studies tend to measure behaviour through self-report. Furthermore, like the FOBt, antenatal screening is a distinct and perhaps unfamiliar behaviour that is unlikely to require integration into one's daily routine as may be the case for increasing fruit and vegetable consumption. A further note regarding the FOBt is that forming an implementation of when one will complete the test may not be entirely feasible or realistic as completion of the test is dependent on individuals' bowel function.

As mentioned earlier, the field of research focusing on planning interventions is still very limited but likely to develop as more robust research manipulating the effects of different types of planning for specific populations and behaviours emerges. Findings from a recent

systematic review indicate that making plans appears to be efficacious when planning formation is monitored, supervised or when plans are pre-specified (Kwasnicka, Presseau et al. 2013). Moreover, another review by Prestwich and Kellar, (2010) identified several moderators of the effect of implementations including intentions, self-concordance, collaboration with others, plan reminders, global implementation intentions, goal type and conscientiousness. Understanding of these moderating factors helps to identify under what circumstances and for whom interventions that incorporate implementation intentions may be most effective, issues that may be addressing when designing interventions.

This section on intervention strategies has indicated some potentially useful volitional strategies that can be applied to CRC screening to help bridge the gap between intentions and behaviour for people who may otherwise want to participate in screening. None of the studies included in the systematic review of strategies to promote bowel cancer screening uptake by Brouwers et al., (2011) discussed interventions that promoted informed choice and studies measuring informed uptake of screening are on the whole limited. The next section will consider the appropriateness of promoting screening uptake juxtaposed with a policy that advocates informed choice.

## **Should we be designing interventions to promote screening uptake?**

Undergoing screening for most health conditions including CRC is associated with potential harms as well as benefits. Detrimental consequences of screening include anxiety, false positive results (false alarms), false negative result (false reassurance), further invasive investigations such as colonoscopy in CRC screening which carries a risk of bowel perforation, over diagnosis and overtreatment (Austoker 1999). The FOBt is known to have poor predictive value where the vast majority of individuals who receive a 'positive' result do not turn out to have CRC (Moss, Campbell et al. 2012). For those who are found to have the disease detected at screening, the benefits of screening remain dubious (Austoker 1999).

Some people will receive treatment but may still experience recurrence and others may not respond well to treatment and subsequently die. Moreover, there will be some patients who are successfully treated and recover well but they may have done so without screening (Austoker 1999).

Screening is based on the premise that the early detection of disease facilitates earlier treatment and better chances of survival. Screening can thus appear to increase years of survival with the disease, where people whose disease is detected earlier appear to survive longer (Day 1985). However, this lead time bias can distort the perceived efficacy of screening as survival time is measured from the date of diagnosis. Thus, the identification of disease before people have any symptoms gives the impression they survive longer when this may not be the case unless earlier treatment does alter disease outcome (Day 1985). In addition, the efficacy of screening in preventing mortality may be further exaggerated by a length time bias where screening is more likely to detect more slowly growing, less aggressive cancers that are amenable to treatment (Day 1985). The introduction of CRC screening in the UK was done so on the basis of RCT studies involving the FOBt that indicated its ability to reduce CRC related mortality. Later meta-analysis of these studies indicated that the FOBt could reduce CRC mortality by 16% (Hewitson et al., 2008). However, a consistent but not well reported finding is that no reduction in all-cause mortality has been demonstrated by any of the trials involving the FOBt. Some argue that the impact of screening may be restricted to ‘mortality substitution’ where those who would have otherwise died from CRC may have died from other causes (Moayyedi and Achkar 2006). It is equally plausible that CRC screening has no impact on all-cause mortality at all. Either way, achieving widespread public understanding of these inherent limitations of screening is going to be challenging amongst widespread misconceptions. Findings from the qualitative study in this thesis provide subtle hints at these challenges where the majority of participants were positive about screening as a valued health provision that would prevent cancer and in effect, save lives. Nevertheless, given the potentially serious harms of

screening, there is a moral obligation to ensure people being invited for screening are fully aware of the harms and benefits.

### **Promoting informed choice**

Participation is often regarded as the most important marker of success of a screening programme (Andermann, Blancquaert et al. 2008). However, low uptake of screening is not necessarily a negative outcome as long as individuals' choices are consistent with their values and based on good knowledge. There has been increasing interest in focusing on maximisation of informed choice rather than screening participation rates, or focusing on consistency between individuals' preference for decision making and their subsequent screening behaviour as an ideal for successful screening programmes. However, there is concern that people may feel less positive about screening and decide not to participate after receiving information about the limited individual benefits and possible harms of screening. A study by Smith et al., (2010) demonstrated that a FOBt decision aid for a sample of low literacy adults in Australia improved decision making and informed choice but there was significantly lower levels of screening participation in the group who received the decision aid. Furthermore, there are concerns that a differential effect on screening uptake across social groups would result in even lower uptake amongst the more socially deprived (Kellar, Mann et al. 2011). However, there are also benefits of promoting informed choice. Alongside respecting patients' autonomy, evidence suggests that participating in screening after having made an informed choice to do so is likely to be associated with more realistic expectations of screening, with corresponding lower levels of emotional distress and false reassurance (Crockett, Wilkinson et al. 2008).

Despite recommendations for the implementation of screening programmes to be based on informed choice, there are inherent challenges to promoting informed choice. Dialogue with local healthcare professionals inform the author that there are drives to "increase uptake"

with virtually no consideration of informed choice. This suggests a conflict between policy and practice. For cervical cancer screening, payments for general practitioners for reaching screening targets effectively work against the ethos of enabling women to make an informed choice about whether they want to participate in screening or not (Austoker 1999). As CRC screening is organised independently of primary care, perhaps it is not entirely surprising that uptake is low as there is no financial incentive for primary care HCPs to promote screening. However, findings from a recent randomised control trial (Hewitson, Ward et al. 2011) found that receipt of a CRC screening invitation letter that was signed by participants' GP was associated with increased screening participation.

In terms of facilitating informed choices, interventions have predominantly focused on increasing knowledge only (Jepson, Forbes et al. 2001). However, from a theoretical perspective such as the TPB, an increase in knowledge is not expected to produce a significant change in attitudes or behaviour of individuals. Moreover, as mentioned earlier, many psychological theories of behaviour propose that intentions are the proximal determinants of behaviour where attitudes are only important in shaping intentions and are not directly related to behaviour. Thus, there appears to be an inconsistency between the tenets of informed choice and psychological theories of behaviour, which has inadvertently created a tension in promoting screening and promoting informed choice.

One aspect of informed choice that is consistent with the principles of social cognitive theories of behaviour is the assumption that individuals are rational actors who are adept in gaining complete knowledge about the positive and negative consequences of screening, weigh up alternatives and freely select the best option for themselves. Screening invitations are based on written materials, but it is questionable whether all individuals process and understand information about screening in such a rational and deliberative fashion (Marteau, Hollands et al. 2012). However, the existing information that accompanies screening invitations concentrates on deliberative processes is problematic as people are likely to vary

in their cognitive ability to undertake rational, deliberative processing. This may be one reason for the SES inequalities that were evident in informed choices about screening participation in the questionnaire survey.

The provision of balanced information alone does not necessarily guarantee that people will include it in their decision process or that they want to obtain this knowledge (Jepson, Hewison et al. 2005). Simply providing information is insufficient as people may want they opportunity to discuss any concerns they have about screening with HCPs. Results from evaluations of the recent 'National Awareness and Early Diagnosis Initiative' (NAEDI) which included mass media campaigns to promote awareness of the symptoms of various types of cancer, suggest that this did not significantly increase the uptake of CRC screening (Snowball, Young et al. 2012). In addition, despite adequate knowledge and positive attitudes, some people may still not participate in screening due to barriers such as poor physical health or other unpredictable factors (e.g. family emergency) that may prevent individuals from acting in accordance with their choices.

## **Recommendations for future research**

The studies in this thesis have identified which beliefs would be useful to target in an intervention to facilitate informed responses to screening, but this has been carried out in a cross sectional way. In the absence of an experimental manipulation of beliefs, some suggestions for future research examining the uptake of CRC screening in ethnically and socio-economically diverse groups can be made. Firstly, as there are very few studies and interventions are designed to evaluate informed choice, future studies could direct efforts towards developing and testing different methods of maximising choice in cancer screening programmes. Secondly, intervention studies regarding informed choice should explore the utility of volitional behaviour change strategies in improving attitude-behaviour consistency. Informed choice is arguably more difficult to measure than uptake due to its multi-faceted



nature thus adequate operationalisation of the concept is required in order to facilitate its reliable measurement within a screening programme that is embedded in the constraints of a national health service.

The results of this thesis are based on a selected community of South East London. It is possible that the promotion of informed screening in other areas with different ethnic groups may require additional support for potential language barriers, which were not a major concern in South East London. In addition, it would be useful to facilitate a dialogue between those who may otherwise want to be screened but lack knowledge or the ability to plan/regulate their behaviour and relevant information/resource points. The potential role for primary care in enabling action and coping planning in advance of anticipated barriers may be interesting to examine here. Results from the qualitative study and conversations with participants in the questionnaire study strongly suggest people would be willing to discuss screening with others but may not necessarily initiate the discussion themselves. On a practical level, a 'one size' fits all approach may not be appropriate in implementing interventions to encourage the informed uptake of screening and greater tailoring, engagement of groups on a local level, using local resources and healthcare professionals may be required.

## **Concluding comment**

The reduction of inequalities in cancer survival is a key objective of the government's Cancer Reform Strategy. The relatively poor cancer survival rates in the UK have prompted attention towards the early detection of a number of cancers including CRC. However, as outlined throughout this thesis, uptake of screening differed across the population, with considerably lower uptake in certain socio-demographic groups. The findings of this thesis are partly consistent with previous research where uptake of screening was found to differ by ethnicity but inconsistent with research that documents lower uptake in more deprived

groups. These findings require caution due to the relatively small proportions of ethnic minority and more socially deprived groups that were included in the quantitative survey. Nevertheless, uptake of screening by study participants was much higher than previously reported uptake rates but rates of informed choice remained low. The findings of this thesis suggest that not all ethnic minority and socially deprived groups have negative perceptions about CRC screening. Furthermore, this thesis addresses an important gap in research by providing information on the views of Black African and Black Caribbean people in the UK who have not previously been studied as separate groups. Future studies should direct attention towards developing a robust evidence base on effective intervention strategies for diverse populations. There is a need to ensure that the CRC screening programme is a fair and equitable service where everyone has an equal opportunity of making an informed choice, regardless of their ethnic or cultural background and SES.

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## Appendix 4.1 – Systematic Review Search terms

TITLE-ABS-KEY(colorectal) OR TITLE-ABS-KEY(colon\*) OR TITLE-ABS-KEY(rectal) OR TITLE-ABS-KEY(rectum) OR TITLE-ABS-KEY(anal) OR TITLE-ABS-KEY(sigmoid\*) OR TITLE-ABS-KEY(bowel))) AND ((TITLE-ABS-KEY(neoplas\*) OR TITLE-ABS-KEY(tumor\*) OR TITLE-ABS-KEY(tumour\*) OR TITLE-ABS-KEY(cancer) OR TITLE-ABS-KEY(carcinoma) OR TITLE-ABS-KEY(crc)))

AND ((TITLE-ABS-KEY(screen\*) OR TITLE-ABS-KEY(mass screen\*) OR TITLE-ABS-KEY(population surveillance) OR TITLE-ABS-KEY(early detect\*)))

AND ((TITLE-ABS-KEY(faecal occult blood test) OR TITLE-ABS-KEY(fecal occult blood test) OR TITLE-ABS-KEY(fob\*) OR TITLE-ABS-KEY(fobt) OR TITLE-ABS-KEY(colonoscop\*) OR TITLE-ABS-KEY(sigmoidoscop\*))) AND

((TITLE-ABS-KEY(health belief\*) OR TITLE-ABS-KEY(attitude\*) OR TITLE-ABS-KEY(intention\*) OR TITLE-ABS-KEY(emotion\*) OR TITLE-ABS-KEY(fear OR worry) OR TITLE-ABS-KEY(embarrassment OR disgust) OR TITLE-ABS-KEY(outcome expect\*) OR TITLE-ABS-KEY(anticipat\* regret) OR TITLE-ABS-KEY(knowledge) OR TITLE-ABS-KEY(subjective norm\*) OR TITLE-ABS-KEY(perceived behav\* control OR pbc) OR TITLE-ABS-KEY(susceptibility) OR TITLE-ABS-KEY(severity) OR TITLE-ABS-KEY(barrier\*) OR TITLE-ABS-KEY(benefit\*) OR TITLE-ABS-KEY(self efficacy) OR TITLE-ABS-KEY(capabil\*) OR TITLE-ABS-KEY(consequence\*) OR TITLE-ABS-KEY(risk OR perceived risk) OR TITLE-ABS-KEY(motivation) OR TITLE-ABS-KEY(psychological determinant\* OR determinant\*) OR TITLE-ABS-KEY(psychological predictor\* OR predictor\*) OR TITLE-ABS-KEY(psychosocial factor\*) OR TITLE-ABS-KEY(decision) OR TITLE-ABS-KEY(goal\*) OR TITLE-ABS-KEY(action plan) OR TITLE-ABS-KEY(acceptance\*))) AND

((TITLE-ABS-KEY(social class) OR TITLE-ABS-KEY(socioeconomic factor\*) OR TITLE-ABS-KEY(deprivation) OR TITLE-ABS-KEY(social capital) OR TITLE-ABS-KEY(social status) OR TITLE-ABS-KEY(sociodemographic) OR TITLE-ABS-KEY(sociocultural) OR TITLE-ABS-KEY(low income) OR TITLE-ABS-KEY(poverty) OR TITLE-ABS-KEY(socioeconomic status) OR TITLE-ABS-KEY(psychosocial deprivation) OR TITLE-ABS-KEY(education\*))) AND

((TITLE-ABS-KEY(ethnic group\*) OR TITLE-ABS-KEY(minority ethnic group\*) OR TITLE-ABS-KEY(bme) OR TITLE-ABS-KEY(immigrant\*) OR TITLE-ABS-KEY(multi ethnic) OR TITLE-ABS-KEY(ethnic\*) OR TITLE-ABS-KEY(multi racial) OR TITLE-ABS-KEY(minority group\*) OR TITLE-ABS-KEY(african\$) OR TITLE-ABS-KEY(caribbean\$) OR TITLE-ABS-KEY(afro-caribbean\$) OR TITLE-ABS-KEY(black\$) OR TITLE-ABS-KEY(asian\$) OR TITLE-ABS-KEY(chinese\$) OR TITLE-ABS-KEY(indian\$) OR TITLE-ABS-KEY(jamaican\$) OR TITLE-ABS-KEY(pakistan\$) OR TITLE-ABS-KEY(white\$)))

#### Appendix 4.2 Study quality criteria (Sirriyeh et al. 2011)

Quality criterion	Study type applied to
Explicit theoretical framework	All studies
Statement of aims/objectives in main body of report	All studies
Clear description of research setting	All studies
Evidence of sample size considered in terms of analysis	All studies
Representative sample of target group of a reasonable size	All studies
Description of procedure for data collection	All studies
Rationale for choice of data collection tool(s)	All studies
Detailed recruitment data	All studies
Statistical assessment of reliability and validity of measurement tool(s)	Quantitative only
Fit between stated research question and method of data collection	Quantitative only
Fit between stated research question and format and content of data collection tool e.g. interview schedule	Qualitative only
Fit between research question and method of analysis (quant only)	Quantitative only
Good justification for analytic method selected	All studies
Assessment of reliability of analytic process (qualitative only)	Qualitative only
Evidence of user involvement in design	All studies
Strengths and limitations critically discussed	All studies

## **Appendix 5.1 – Participant information sheet (Qualitative)**

### **Explaining Varied Uptake of Bowel Cancer Screening; A Qualitative Study**

#### **Participant Information Sheet**

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of this study?**

In 2006 the NHS National Bowel Cancer Screening Programme started offering screening for bowel cancer every two years to men and women aged between 60 to 69 years. People in this age group are sent an invitation through the post and then sent their screening kit so they can do the test at home. The test is called the Faecal Occult Blood test (FOBT - this means testing for blood in your stools which could be an indicator of cancer). Studies show that while some people in this part of London, do the test, others don't. We want to find out why this is.

In this study, we would like to find out the thoughts of the people in Lambeth on bowel cancer screening and the FOBT screening test. We hope to use the findings to improve information for people considering having screening for bowel cancer. We also want to find out more about the factors that might be helping or preventing people from doing the FOBT, so that we can try to make sure that people who want bowel cancer screening are able to have it. This study is being undertaken as part of the researcher's PhD degree in health psychology.

### **Why have I been invited?**

We are inviting men and women aged between 55 to 75 years registered with general surgeries in Lambeth to take part in this study. We especially want to hear the views of people from African and Caribbean backgrounds as currently very little is known about their thoughts on screening for bowel cancer.

### **Who can take part in this study?**

To take part in this study you should be:

- Aged between 55 to 75 years
- Of African, Caribbean or White British origin
- Able to converse fluently in English
- Physically and mentally able to take part in an interview

However you should not take part if you have recently been diagnosed with cancer, are already having regular bowel examinations, have ever been told by your doctor you have a genetic bowel cancer syndrome such as familial adenomatous polyposis or are at risk of getting hereditary non-polyposis colon cancer.

### **Do I have to take part?**

It is up to you to decide whether or not you would like to take part. If you are interested in taking part or would like more information about the study, please let the surgery receptionist, your GP or nurse know, when you see them. The researcher will then come and speak to you about the study or she can telephone you later, if you wish. Your care from your doctor or nurse will not be affected in any way if you decide not to take part in this research.

### **What will happen to me if I take part?**

If you decide to take part, you will be given this information sheet to keep and asked to sign a consent form. You will then take part in an interview at the surgery with an

experienced researcher. The interview will be arranged at a time that is convenient for you and you will be offered a choice of times. The interview may take up to an hour to complete and will ask about your views on the FOBt, how you might feel if you were asked to complete it and the types of things you would think about when deciding whether to do so. With your permission, the interview will be recorded using a digital recorder. The interview recordings will be deleted once they have been transcribed. After the interview, you will be asked to complete a form containing a few questions about you; for example whether you have previously completed the FOBt, who you live with and whether you are working. After taking part, you are still free to withdraw at any time and without giving a reason.

### **What are the possible benefits of taking part?**

Taking part in this research may not have any direct benefit to you. However, the information you provide will be helpful in providing feedback to the National Bowel Cancer Screening Programme to ensure everyone offered screening has an equal opportunity to complete it.

### **Will my taking part in this study be kept confidential?**

All information gathered will be treated confidentially. All participant names and other details mentioned in the interview will be changed so your identity is kept private. Only the researcher and her supervisors will have access to the interview data. All records will be held securely in our research unit. Your GP will be informed you have taken part in this study with your permission.

### **What will happen to the results of this study?**

At the end of the study we will analyse the information gathered from all the participants. The results are likely to be published in an academic journal. The results may be used to plan future research by our team. No participants will be identified by name in any report or publication.



**Who is organising and funding the research?**

This research is funded in collaboration with Kings College London and Kings College Hospital Charity and is part of a PhD project being completed by the main researcher, Nimarta Dharni.

This study has been reviewed and given favourable opinion by the Outer North East London Research Ethics Committee.

**Thank you for reading this information sheet****Further information**

If you have any questions or would like further information about the study please contact the researcher Miss Nimarta Dharni on 0207 8488733.

If you would like to give any feedback about the study or have any complaints please contact Dr Alison Wright on 0207 8486605, or speak to your GP.

## Appendix 5.2 : Participant consent form

### Explaining Varied Uptake of Bowel Cancer Screening; A Qualitative Study Participant consent form

Name of researcher: Miss Nimarta Dharni  
Division of Health and Social Care Research  
Kings College London  
7<sup>th</sup> Floor Capital House  
42 Weston Street  
London, SE1 3QD

This is a study involving:-

A single interview about people's views, attitudes and beliefs about bowel cancer screening

.....  
(Please initial each box)

I agree to participate in this study

☐

I have read the Participant Information Sheet (Version 2: 29 Jan 2010)  
and had the opportunity to ask questions about it

☐

I understand that I am under no obligation to take part in this study  
and that a decision not to participate will not alter the treatment that I would normally  
receive;

☐

I understand that I have the right to withdraw from this study at any stage and that  
doing so will not affect my treatment;

☐

I agree for my interview to be audio-recorded

☐

I understand that my interview will be audio-recorded and the recording will be  
deleted once it has been transcribed.

☐

I agree for my GP to be informed I have taken part in this study

☐

\_\_\_\_\_  
Participant Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

### **Appendix 5.3 Letter of thanks**

Date:

Dear

Re: Screening for bowel/colorectal cancer interview study

Thank you very much for taking part in our study on (date). The information that you gave will be very useful to help us understand what people of different backgrounds think about the Faecal Occult Blood Test (FOBt) used in the bowel cancer screening programme. We also hope to understand more why some people in south east London are completing the test whilst others are not. We hope from this work we will be able to make recommendations to the National Bowel Cancer Screening Programme to consider the factors preventing people from doing the FOB test and incorporate those that encourage completion. Overall we hope the information from this study will be used to help more people make an informed choice about taking part in bowel cancer screening.

If you asked for a copy of the results of this study, it will be posted to you in summer 2010, when we hope the study will be complete. Please do not hesitate to contact me in the mean time if you would like any more information about the study.

With good wishes

Yours sincerely

Miss Nimarta Dharni  
PhD Research Student  
Kings College London

Tel: 0207 8488733  
e-mail: Nimarta.Dharni@kcl.ac.uk

## Appendix 5.4 Socio-demographic questionnaire

### Questions about you

1. Have you received an invitation to take part in the bowel cancer screening programme in the last two years?  
☐ Yes      ☐ No      ☐ Prefer not to say
2. Have you completed the Faecal Occult Blood Test as part of the bowel cancer screening programme?  
☐ Yes      ☐ No      ☐ Prefer not to say
3. If yes, how many times have you completed the test?  
☐ Once  
☐ Twice  
☐ Three times  
☐ Four times or more  
☐ Prefer not to say
4. Please give the month and year when you completed the test if you can remember  
.....
5. Please state your age in years.....
6. Have you ever had a diagnosis of cancer in the past?  
☐ Yes      ☐ No      ☐ Prefer not to say
7. Has anyone close to you (e.g. parent, sibling, partner, friend, other) presently or in the past been diagnosed with bowel cancer?  
☐ Yes      ☐ No      ☐ Prefer not to say
8. Are you:  
☐ Single (never married)  
☐ Married or living with a partner  
☐ Divorced/separated  
☐ Widowed  
☐ Other (please specify).....
9. Do any of the following people live in your household with you?  
(Please tick all of the boxes that apply):  
☐ Wife/husband/ partner  
☐ Child(ren)  
☐ Parent(s)

- ☐ Other relatives
- ☐ Friend(s)
- ☐ I live alone
- ☐ Other (please specify).....

10. Does your household own or have use of a car or van?  
☐ Yes    ☐ No    ☐ Prefer not to say

11. Please tick the box which best describes your accommodation:

- ☐ Own your own home (including if with a mortgage)
- ☐ Renting from a private landlord
- ☐ Renting from Housing Association
- ☐ Renting from the council
- ☐ Living in temporary accommodation
- ☐ Other (please specify).....

12. Which of the following best describes your usual situation?

- ☐ Full time employment
- ☐ Part time employment
- ☐ Unemployed
- ☐ Retired
- ☐ Retired early
- ☐ Homemaker
- ☐ Other (please specify).....

13. Please indicate your highest level of formal educational qualification  
 (please tick only one box)

- ☐ Postgraduate degree (e.g. PgDip, MSc, MA, MBA, PhD)
- ☐ Undergraduate degree (e.g. BSc, BA, BEng)
- ☐ Other type of higher education (e.g. HND, HNC, Nursing qualifications)
- ☐ A Levels/NVQ3
- ☐ Further education (e.g. NVQ level 2, City and Guilds, BTec diploma)
- ☐ GCSEs/O levels/CSEs
- ☐ No formal qualifications
- ☐ Other formal qualifications (please specify) .....
- ☐ Prefer not to say

14. How long have you been living in the UK?

- ☐ From birth
- ☐ Over 10 years
- ☐ 5 – 10 years
- ☐ Less than 5 years
- ☐ Prefer not to say

15. How would you describe your ethnic group?

- ☐ White British
- ☐ White Irish
- ☐ Any other White background (please specify).....
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed background (please specify).....
- ☐ Caribbean
- ☐ African
- ☐ Any other Black background (please specify).....
- ☐ Any other ethnic group (please specify).....
- ☐ Prefer not to say

16. What languages do you speak?

.....

17. What is your preferred language to speak?

.....

**Thank you for completing this questionnaire**

## **Appendix 5.5 Themes generated from the first round of familiarisation**

The first round of familiarisation with the data was undertaken with interview transcripts P7, P17, P22 and P23. Transcripts were read openly and the following themes were identified from each transcript:

### **P7**

- Knowledge of cancer (page 1)
  - Bowel cancer
  - Symptoms
  - Causes
- Participation in other screening programmes (page 2)
  - Breast screening
- Nature of the test (page 3)
  - “Messing about” – perhaps reference to complicated completion or literal ‘mess’ to faecal matter
  - Concerns about smell
  - Thought of handling and collecting faecal sample “horrible”
  - Would find Fobt completion physically awkward due to “bad knees” (page 5)
  - Misunderstanding what was involved (page 6)
  - Use of “silly sticks” (page 8)
  - Would prefer fobt to sigmoidoscopy as less intrusive (page 9)
- No symptoms hence no worry “regular as clockwork” (page 4)
  - Presence of symptoms would encourage screening completion and helping seeking for further tests (page 4 and 8)
- Lack of confidence in completing Fobt (page 7)
- Benefits of screening (page 8)
  - Detect cancer
- Fear of cancer (page 8)
  - Not wanting to think about cancer
- Lower motivation to know about health problems as get older (page 8)
- Emotions (page 10)
  - “Horried” at receipt of test - not wanting to look at the kit
  - Anticipated fear cancer might be detected
  - Anxious waiting for results
- Unexpected screening invite “landed on the doorstep” (page 10)
- Intention to complete screening
  - Unlikely to do

### **P17**

- Easy to do (p1)
  - Provided with all tools to complete the test (p6)

- Participation in other screening programmes (Breast) (p2)
  - Invited to attend
  - Attend because invited (p5)
  - Believes in screening (p5)
- Positive attitude towards screening “excellent” (p2)
- Simplicity of kit (p3)
- Discreteness of test (p3)
  - Through the post (p3)
  - Privacy (p11)
  - No one else needs to know (p11)
- Queries about screening programme
  - on collection of sample (p3)
  - bowel motion and screening completion – diarrhoea/piles (p4)
  - Identify at screening stage reason of presence of blood in stools (p5)
- Screening gives peace of mind (p5)
- Would feel 100% confident completing screening
- Importance of early detection (p6)
  - Easier to treat (p7)
  - Acknowledgement may not be cured but will help treatment if detected early (p9)
- Would regret not participating in screening if cancer detected (p6)
- Would question why it wasn’t detected early or why screening wasn’t available (p6)
- Screening introduced for people’s benefit (p6)
- Concerned if test got lost in post (p6)
- Screening saves lives (p7)
- Increasing motivation to look after oneself as getting older (p8)
  - “Want to live
- Screening as a choice (p8)
  - “Choice to live or die”
- Experience of cancer being detected in significant others through screening (p9)
- Views of others on screening would not influence own decision to participate (p10)
- Would worry if thought cancer might be detected (p10)
- Nervous whilst waiting for results (p10)
- Would be embarrassing if had to have sample collected by someone else (p11)
- Intention
  - “100%” likely to complete test when invitation arrives

## **P22**

- Lack of knowledge of bowel cancer (p1)
- Screening is a “good idea” (p3)
  - as may be caught on time
  - Easier to treat and therefore prolong life
- Had difficulty completing the test (p3)
  - Novelty of test



- Made a mistake during day 1 completion, but fine thereafter
  - Would help if kit and sticks were bigger, in case they break (p4)
- Previous knowledge of someone with cancer (p4)
  - Association of cancer with pain slow death (p10)
  - Lack of control over diseased body (p10)
- More confident completing test during second screening round (p4)
- Best to check in case anything is wrong (p4)
- Would ask partner to help with test completion (p5)
- Benefits of screening (p5)
  - “if anything wrong”
  - Early detection helps treatment before too advanced
  - Anticipated regret if didn’t have screening and later got cancer or advanced cancer diagnosed “no hope”
  - “Can save lives” (p6)
  - “Better to be safe” – unpredictable nature of life (p7 and 8)
- Important to know if anything wrong with own body (p5)
  - Cancer as a threat to life as ageing (p5)
  - Death and implications for self and partner (p8)
  - Screening important for prolonging life (p8)
  - Desire to age gracefully (p8)
- Appropriateness of discussing screening (p6)
  - Would discuss with partner
  - Not an everyday subject – would not want to offend
  - Embarrassment of talking about bowels (p9)
  - Fear of being ridiculed (p9)
- “Petrified” when received test (p8)
  - Thought of bowel cancer
  - Would not be able to cope if had cancer (p10)
  - Contemplate prognosis if had cancer and get depressed (p10)
- Having check-ups – attends foot health monitoring clinic (p8)
  - Best to monitor all parts of the body
- Timing of test completion and upkeep of daily routine (p9)
  - Need to be in the morning as attends luncheon clubs
- Perception of barriers for others (p9)
  - Fear or embarrassment of doing test
  - Preference to “live with it” rather than undergo treatment
  - Lack of awareness and hiding of problems (p11)
- Motivation for screening (p10)
  - Not wanting to suffer like the known person he has known (p10)

## **P23**

- Perception of cancer (p1)
  - Generalisation as a ‘nasty illness’
  - Association with death (p6)
  - Cannot be prevented (p8)
- Previously not participated in any screening therefore low awareness (2)

- Personality (p2)
  - “naturally reticent”
  - Not wanting to be personally involved (p3)
  - Prefer not to know as “no news is good news” (p3)
  - Not enthusiastic about screening (p2)
  - Not wanting to go down the road of cancer treatment (p4)
  - Would find it difficult to complete FOBt as a private person (p10)
- Screening as invasion of privacy (p2)
- Put off by faecal sample (p2)
  - “messy”
  - queries on size of the sample
- Straightforward to do (p3)
- Would not voluntarily engage in screening as generally healthy (p4)
- Not participating due to fear of cancer (p4)
- Queries about storage of the kit (p5)
- Stigma of cancer (p5)
- Startled at receipt of screening invitation and test (p5)
- Previous experience of people with cancer (p5)
- Screening as a “good idea” (p6)
  - Prevention of pain
  - X-ray analogy
  - Advanced warning of cancer
  - Good intentions of screening programme (p7)
- But would need “courage” to complete (p6)
  - Not wanting to “take the plunge” in case cancer detected (p8)
  - Anxiety over results (p10)
  - Fear cancer may be detected (p10)
- Effect of upbringing (p6)
  - Formality of upbringing vs. informal nature of screening
- Important to do as greater risk with age (p8)
  - Increasing ailments as getting older
- Maybe influenced to take part in screening by someone he trusts (p9)

## Appendix 5.6 Study approvals

### **National Research Ethics Service**

#### **East London REC 3**

Board Room A  
2nd Floor  
Becketts House  
2/14 Ilford Hill  
Ilford  
Essex  
IG1 2QX

Tel: 020 7188 2259  
Fax: 020 7188 2258

29 April 2010

Miss Nimarta Dharni  
PhD Student  
King's College London  
Division of Health and Social Care Research  
7th Floor Capital House  
42 Weston Street  
London SE1 3QD

Dear Miss Dharni

**Study title:** Explaining Differences in Bowel Cancer Screening  
Uptake in South East London; Exploration of Ethnic and  
Socio-Economic Variation through a Qualitative Study  
**REC reference:** 10/H0701/2  
**Amendment number:** AM01  
**Amendment date:** 19 April 2010

#### **Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	2	16 April 2010
Notice of Substantial Amendment (non-CTIMPs)	1.0	19 April 2010

#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the Health Research Authority (HRA) in London

Public Health Department  
Hub 2 1<sup>st</sup> Floor  
PO Box 64529  
London  
SE1P 5LX  
Tel: 020 7525 0289  
Fax: 020 7525 0318  
email: [anne.grant@southwarkpct.nhs.uk](mailto:anne.grant@southwarkpct.nhs.uk)  
[www.researchdevelopmentcentre.nhs.uk](http://www.researchdevelopmentcentre.nhs.uk)

Ms Nimarta Dharni  
Department of Primary Care and Public Health Sciences  
King's College London  
9<sup>th</sup> fl Capital House  
42 Weston Street  
London  
SE1 3QD

8<sup>th</sup> March 2010

Dear Ms Dharni

**Project Title: Explaining the differences in Bowel Cancer Screening uptake in South East London: Exploration of ethnic and socio-economic variation through a qualitative study**  
**R & D Reference: RDLAM 527**

Thank you for your assistance providing the documentation for the scrutiny of this project.

I am satisfied that this study meets with the requirements of the Research Governance Framework. It has been approved by the research lead for the respective NHS organisation.

Approval is given on behalf of NHS Lambeth on the understanding that you adhere to the conditions on the attached document. The end date of the project is listed as 1<sup>st</sup> September 2010

If you require any further information, please contact Dr Anne Grant on 020 7525 0289.

Yours sincerely

**Hiten Dodhia**

Consultant in Public Health and R&D lead for NHS Lambeth  
Chair of the Research Management Group for South East London NHS  
Bexley, Bromley, Greenwich, Lambeth, Lewisham & Southwark



**Bowel Cancer Screening Programme  
Research Committee**

**Professor John Scholefield**  
Chair

**Gillian Liddington**  
Administrator

NCRI Clinical Studies Groups Secretariat  
PO BOX 123  
61 Lincoln's Inn Fields  
London  
WC2A 3PX

Miss Nimarta Dharmi  
[Nimarta.Dharmi@kcl.ac.uk](mailto:Nimarta.Dharmi@kcl.ac.uk)

Tel: 020 7061 8533  
Fax: 020 7061 8581

[gillian.liddington@cancer.org.uk](mailto:gillian.liddington@cancer.org.uk)

09 April 2010

Dear Miss Dharmi

The Bowel Cancer Screening Programme (BCSP) Research Committee met on 12 March 2010 to discuss your research plans: **Explaining Varied Uptake of Bowel Cancer Screening in South East London; Exploration of Ethnic and Socio-Economic Variation**

The Committee noted that this research has been resubmitted with a summary and protocol. The Committee was pleased that you have taken advice and feedback from Professor Weller.

The Committee considered that this is good research and supported the project in its initial phase. The Committee would like the project brought back to them at the intervention phase.

The Committee is due to meet again in June and September 2010. Deadlines for submitting further research for consideration by the Committee will be four weeks before the meeting, namely by 10 am; 31 May and 3 September.

We would like you to keep us informed of developments with the study and wish you well with your research.

Yours sincerely

**Gillian Liddington**  
On behalf of the NHS Bowel Cancer Screening Programme Research Committee

## **Appendix 6.1- Study approvals**

### **NRES Committee London - East**

REC Offices  
Room 10  
4th Floor West  
Charing Cross Hospital  
Fulham Palace Road  
London W6 8RF  
Telephone: 020 3311 7227  
Facsimile: 020 3311 7280

Miss Nimarta Dharni  
PhD Student  
Kings College London  
Division of Health and Social Care  
Research, 7th Floor Capital House,  
42 Weston Street, London  
SE1 3QD

01 August 2011

Dear Miss Dharni

**Study title:** Explaining Differences in Bowel Cancer Screening  
Uptake in South East London; Exploration of Ethnic and  
Socio-Economic Variation through a Qualitative Study  
**REC reference:** 10/H0701/2  
**Protocol number:** N/A  
**Amendment number:** 03  
**Amendment date:** 20 July 2011

#### **Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Questionnaire 2 20 July 2011  
Notice of Substantial Amendment (non-CTIMPs) 03 20 July 2011

#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**10/H0701/2: Please quote this number on all correspondence**

Yours sincerely

**Dr Elizabeth Webster**  
**Vice Chair**

E-mail: [atul.patel@imperial.nhs.uk](mailto:atul.patel@imperial.nhs.uk)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to:*

*Sponsor:*

Dr Alison Wright  
King's College London  
Division of Health and Social Care Research  
7th Floor Capital House  
42 Weston Street  
London SE1 3QD

*R&D*

Dr Anne Grant  
Lambeth and Southwark Primary Care Trust  
2<sup>nd</sup> Floor, Woodmill Building  
Neckinger  
London SE16 3QN



*Bowel Cancer Screening Programme  
Research Committee*

Professor John Scholefield  
Chair

Mrs Gillian Liddington  
Administrator

Miss N Dharni  
[nimarta.dharni@kcl.ac.uk](mailto:nimarta.dharni@kcl.ac.uk)

NCRI Clinical Studies Groups Secretariat  
Angel Building  
407 St John Street  
London  
EC1V 4AD

Tel: 020 3469 8533

[gillian.liddington@cancer.org.uk](mailto:gillian.liddington@cancer.org.uk)

09 February 2011

Dear Miss Dharni

The Bowel Cancer Screening Programme (BCSP) Research Committee is satisfied that you met their conditions of support for your project: **Explaining Varied Uptake of Bowel Cancer Screening in South East London; Exploration of Ethnic and Socio-Economic Variation.**

The Committee give their support to the project and are happy for you to proceed.

This letter of support can be used as permission to gain the relevant access to the Screening Programme.

We would like you to keep us informed of developments with the project such as

- when the sample size is determined
- when ethical approval is obtained
- when research project has started
- when fully recruited
- any change of status
- any significant adverse reactions
- when complete and
- when written up (including a copy of your findings for the Committee)

We wish you well with your research.

Yours sincerely

Gillian Liddington  
On behalf of the NHS Bowel Cancer Screening Programme Research Committee



Southwark Public Health  
Department  
Hub 2 1<sup>st</sup> Floor  
PO Box 64529  
London  
SE1P 5LX  
Tel: 020 7525 0289  
Fax: 020 7525 0318  
email: [anne.grant@southwarkpct.nhs.uk](mailto:anne.grant@southwarkpct.nhs.uk)  
[www.researchdevelopmentcentre.nhs.uk](http://www.researchdevelopmentcentre.nhs.uk)

Ms Nimarta Dharni  
Division of Health and Social Care Research  
7th Floor Capital House  
42 Weston Street  
London  
SE1 3QD

20/04/2011

Dear Ms. Dharni

Project Title: Explaining Differences in Bowel Cancer Screening Uptake in South East London; Exploration of Ethnic and Socio-Economic Variation through a Qualitative Study.  
R & D Reference: RDLSou 527

Thank you for your assistance providing the documentation for the scrutiny of this project.

Following review of amendment 2 for the above study submitted on 18/03/2011 NHS Lambeth and Southwark have decided that we can accommodate this amendment.

These sites can therefore continue to participate in the study. The end date of the project is listed as 1st September 2012.

If you require any further information, please contact Ali Alshukry on 020 7525 0264.

Yours sincerely

**Dr Anne Grant**  
RG & M Manager  
South East London NHS  
Bexley, Bromley, Greenwich, Lambeth, Lewisham & Southwark

Guy's, King's  
and St Thomas'  
School of Medicine  
Department of Primary Care &  
Public Health Sciences

**Head of Department**  
Professor Brendan Delaney

7th Floor, Capital House  
42 Weston Street  
London SE1 3QD  
Tel 020 7848 8734  
Fax 020 7848 6620  
Email gp@kcl.ac.uk



## Appendix 6.2 – Invitation letter

Dear

I am writing to ask you if you would like to take part in a research study I am doing as part of my PhD studies in the Department of Primary Care and Public Health Sciences at King's College London. There is an information sheet with this letter for you to read with further information about the study.

If you choose to take part, you will complete a survey on the telephone about your views about screening for bowel cancer. As a token of thanks for your participation in the survey, you will receive a £20 gift voucher.

The aim is to find out the thoughts of the people in Lambeth and Southwark on bowel cancer screening as screening rates are very low in these areas. However little is known about the reasons why. We hope to use the findings to improve information and make sure that people who want bowel cancer screening are able to have it. I am working with the NHS Bowel Cancer Screening Programme to carry out this work.

If you think you would be interested in taking part, please return the enclosed slip with your contact details and signed consent form, in the envelope provided. If you would like to find out more about the study, please phone the study researcher Ms Nimarta Dharni, directly on 020 7848 8733. Calling or writing for further information does not mean you have to take part. Please note that the service you receive from Bowel Cancer Screening Programme will not be affected in any way and we will not be sharing any information with them. All information is strictly confidential and securely kept.

If we do not hear from you, we will send you a second invitation letter in two weeks. If you do not wish to take part, please tick the appropriate box on the enclosed slip, return it to us and we will not contact you again about this research.

We do hope you will be able to help us in supporting this study.

With good wishes,

Guy's, King's  
and St Thomas'

School of Medicine

Department of Primary Care &  
Public Health Sciences

**Head of Department**  
Professor Brendan Delaney

7th Floor, Capital House  
42 Weston Street  
London SE1 3QD  
Tel 020 7848 8734  
Fax 020 7848 6620  
Email gp@kcl.ac.uk



Ms Nimarta Dharni  
PhD student  
Kings College London  
Tel: 0207 848 8733

## **Appendix 6.3 – Participant information sheet**

### **Explaining Varied Uptake of Bowel Cancer Screening; A Questionnaire Study**

#### **Participant Information Sheet**

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of this study?**

In 2006 the NHS National Bowel Cancer Screening Programme started offering screening for bowel cancer every two years to men and women aged between 60 to 69 years. People in this age group are sent an invitation through the post and then sent their screening kit so they can do the test at home. The test is called the Faecal Occult Blood test (FOBT - this means testing for blood in your stools which could be an indicator of cancer). Studies show that while some people in this part of London, do the test, others don't. We want to find out why this is.

In this study, we would like to find out the thoughts of the people in Lambeth and Southwark on bowel cancer screening and the FOBT screening test. To gather this information, we have developed a questionnaire from previous in-depth interviews with a selection of people living in Lambeth and Southwark. We hope to use the findings to improve information for people considering having screening for bowel cancer. We also want to find out more about the factors that might be helping or preventing people from doing the FOBT, so that we can try to make sure that people who want bowel cancer

screening are able to have it. This study is being undertaken as part of the researcher's PhD degree in health psychology.

**Why have I been invited?**

We are inviting men and women aged between 60 and 69 years, living in Lambeth and Southwark who are within the current age range of the bowel cancer screening programme. We especially want to hear the views of people from African and Caribbean backgrounds as currently very little is known about their thoughts on screening for bowel cancer.

**Who can take part in this study?**

To take part in this study you should be:

- Aged between 60 and 69 years.
- Able to converse fluently in English
- Be contactable by telephone

**Do I have to take part?**

It is up to you to decide whether or not you would like to take part. If you are interested in taking part or would like more information about the study, please return the enclosed reply slip with your contact details and signed consent form, in the envelope provided. If you would like to find out more about the study, please phone the study researcher Ms Nimarta Dharni, directly on 020 7848 8733. Calling or writing for further information does not mean you have to take part. Please note that the service you receive from Bowel Cancer Screening Programme will not be affected in any way and we will not be sharing any information with them. All information is strictly confidential and securely kept. If we do not hear from you within 2 weeks, we will send you a second invitation letter. Again, if we do not hear from you 2 weeks after the second invitation letter, we will not contact you again about this research.

**What will happen to me if I take part?**

If you decide to take part, please sign the enclosed consent form and reply-slip with your contact details in the freepost envelope provided. The researcher will then telephone you to arrange a telephone interview at a time that is convenient for you and you will be offered a choice of times. During the interview, we will complete a single questionnaire containing questions about your views on the FOBt, how you might feel if you were asked to complete it and the types of things you would think about when deciding whether to do so. The interview may take up to 30 minutes to complete. After taking part, you are still free to withdraw at any time and without giving a reason. With your permission, the researcher will

receive information from the Bowel Cancer Screening Programme whether a FOBt kit is returned by you in the future. The researcher will not have any access to any of your personal records or your screening test result, if you choose to complete the test. As a token of our appreciation of your help with this research, you will receive a £20 gift voucher.

**What are the possible benefits of taking part?**

Taking part in this research may not have any direct benefit to you. However, the information you provide will be helpful in providing feedback to the National Bowel Cancer Screening Programme to ensure everyone offered screening has an equal opportunity to complete it.

**Will my taking part in this study be kept confidential?**

All information gathered will be treated confidentially. All participant names and other details will be changed so your identity is kept private. Only the researcher and her supervisors will have access to the data. All records will be held securely in our research unit.

**What will happen to the results of this study?**

At the end of the study we will analyse the information gathered from all the participants. The results are likely to be published in an academic journal. The results may be used to plan future research by our team. No participants will be identified by name in any report or publication.

**Who is organising and funding the research?**

This research is funded in collaboration with Kings College London and Kings College Hospital Charity and is part of a PhD project being completed by the main researcher, Nimarta Dharni.

This study has been reviewed and given favourable opinion by the Outer North East London Research Ethics Committee and the Bowel Cancer Screening Research Committee.

**Thank you for reading this information sheet**

**Further information**

If you have any questions or would like further information about the study please contact the researcher Miss Nimarta Dharni on 0207 8488733.

Guy's, King's  
and St Thomas'

School of Medicine

Department of Primary Care &  
Public Health Sciences

**Head of Department**  
Professor Brendan Delaney

7th Floor, Capital House  
42 Weston Street  
London SE1 3QD  
Tel 020 7848 8734  
Fax 020 7848 6620  
Email gp@kcl.ac.uk



If you would like to give any feedback about the study or have any complaints please contact Dr Alison Wright on 0207 8486605

## Appendix 6.4 – Participant consent form

### Explaining Varied Uptake of Bowel Cancer Screening; A Questionnaire Study

#### Participant consent form

Name of researcher: Miss Nimarta Dharni  
Division of Health and Social Care Research  
Kings College London  
7<sup>th</sup> Floor Capital House  
42 Weston Street  
London, SE1 3QD  
0207 848 8733

This is a study involving:-

A single telephone interview to complete a questionnaire about people's views, attitudes and beliefs about bowel cancer screening

.....

(Please initial each box)

I agree to participate in this study and for the researcher to contact me by telephone

☐

I have read the Participant Information Sheet (Version 3: 17 Mar 2011)  
and had the opportunity to ask questions about it

☐

I understand that I am under no obligation to take part in this study  
and that a decision not to participate will not alter the service I receive from with the Bowel  
Cancer Screening Programme.

☐

I understand that I have the right to withdraw from this study at any stage without providing  
a reason.

☐

I agree to the researcher receiving information if a bowel cancer screening test kit is returned  
by me or not. I understand the researcher will not have any access to my personal records or  
my screening test result, if I choose to complete the test.

☐

\_\_\_\_\_  
Participant Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Appendix 6.5 – Reply slip**

**Explaining Varied Uptake of Bowel Cancer Screening; A Questionnaire Study**

*If you have any questions before sending this reply slip back then please call the researcher  
Ms Nimarta Dharni on 0207 848 8733*

**Name:**.....**Signature:**.....

Please tick as appropriate:

☐

Yes, I would like to know more about this study. Please contact me on the following telephone number.

My telephone number is \_\_\_\_\_

A good date and time to call will be \_\_\_\_\_

☐

No, I would prefer not to learn more about this study. Please do not contact me with any further information.

*Please return this reply slip to the researcher using the stamp-addressed envelope provided.*

**Guy's, King's  
and St Thomas'  
School of Medicine**

Department of Primary Care &  
Public Health Sciences

**Head of Department**  
Professor Brendan Delaney

7th Floor, Capital House  
42 Weston Street  
London SE1 3QD  
Tel 020 7848 8734  
Fax 020 7848 6620  
Email gp@kcl.ac.uk



## **Appendix 6.6 –Second invitation letter**

Dear

I wrote to you a couple of weeks back inviting you to take part in a research study I am doing as part of my PhD studies in the Department of Primary Care and Public Health Sciences at King's College London. In case you did not get round to replying or did not receive the letter, we are providing a second opportunity to take part. If you have recently replied to my earlier letter, please ignore this letter.

There is an information sheet with this letter for you to read with further information about the study. If you choose to take part, you will complete a survey on the telephone about your views about screening for bowel cancer. As a token of thanks for your participation in the survey, you will receive a £20 gift voucher.

The aim of this research is to find out the thoughts of the people in Lambeth and Southwark on bowel cancer screening as screening rates are very low in these areas. However little is known about the reasons why. We hope to use the findings to improve information and make sure that people who want bowel cancer screening are able to have it. I am working with the NHS Bowel Cancer Screening Programme to carry out this work.

If you think you would be interested in taking part, please return the enclosed slip with your contact details and signed consent form, in the envelope provided. If you would like to find out more about the study, please phone the study researcher Ms Nimarta Dharni, directly on 020 7848 8733. Calling or writing for further information does not mean you have to take part. Please note that the service you receive from Bowel Cancer Screening Programme will not be affected in any way and we will not be sharing any information with them. All information is strictly confidential and securely kept.

If we do not hear from you within 2 weeks, we will not contact you again about this research. Many thanks for your time reading this letter.

We do hope you will be able to help us in supporting this study.

With good wishes,

Ms Nimarta Dharni  
PhD student  
Kings College London



**Guy's, King's  
and St Thomas'  
School of Medicine**

Department of Primary Care &  
Public Health Sciences  
Tel: 0207 848 8733

**Head of Department**  
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Tel 020 7848 8734  
Fax 020 7848 6620  
Email [gp@kcl.ac.uk](mailto:gp@kcl.ac.uk)



## **Appendix 6.7 – Participant thank you letter**

Dear

Re: Screening for bowel cancer screening questionnaire study

Thank you very much for taking part in our study on (date). The information that you gave will be very useful to help us understand what people of different backgrounds think about the Faecal Occult Blood Test (FOBT) used in the bowel cancer screening programme. We also hope to understand more why some people in south east London are completing the test whilst others are not. We hope from this work we will be able to make recommendations to the National Bowel Cancer Screening Programme to consider the factors preventing people from doing the FOB test and incorporate those that encourage completion. Overall we hope the information from this study will be used to help more people make an informed choice about taking part in bowel cancer screening.

Please find enclosed a £20 gift voucher as thanks for your participation and help in our study. Please do not hesitate to contact me if you have any further questions or would like any more information about the study.

With good wishes

Yours sincerely

Miss Nimarta Dharni  
PhD Research Student  
Kings College London

Tel: 0207 8488733  
e-mail: [Nimarta.Dharni@kcl.ac.uk](mailto:Nimarta.Dharni@kcl.ac.uk)

## **Appendix 6.8- Questionnaire**

### *Appendix 6.8- Questionnaire*

#### **Bowel Cancer Screening Questionnaire**

Thank you for agreeing to take part in this questionnaire survey. We are interested in finding out what people think about bowel cancer screening as there is not very much information about this. We have developed the questionnaire from previous work with people in this area to find out what people in south east London think about bowel cancer screening and the screening test that is used to carry out screening. We know not many people complete this test but we are not sure of the reasons why so that is the aim of this research. The test is called the Faecal Occult Blood test (FOBt), have you heard about it before or received it through the post?

*If yes then continue to instructions below.*

#### **If no:**

I'll just tell you a little bit about the test before we start as it may help you to answer the questions. Bowel cancer screening is for all men and women in England aged between 60 to 69 years currently being extended from 60-74 years). The FOBt screening test is a small cardboard kit that is posted to people's homes. It requires people to put a small sample/smear from their stool onto the kit for 3 days. People have 2 weeks to complete the test so the samples can be from any three days within the 2 week period. Once completed, the FOBt is posted back in an envelope it came with, to the lab where it is analysed for any hidden traces of blood that may be present. The lab writes back to the person and their GP with the results of the test back within 1-2 weeks. People are automatically invited to take part in screening every 2 years until they reach the upper age limit.

#### **Instructions**

I will read each question to you together with the reply options. Please select the option that best describes your answer, or let me know if you would prefer not to answer any question.

If you are not completely sure which response is the most accurate, select the option you feel is the most appropriate. Please remember this is not a test, we are just interested in finding out your views about bowel cancer screening.

Do let me know if you would like me to repeat a question, or if any question is not clear.

All responses will remain anonymous and confidential.

Also please remember we can stop the questionnaire at any point if you feel you do not want to continue. Taking part in this research will not influence the service you receive from the Bowel Cancer Screening Programme and the results of this survey will not be shared with the programme.

Do you have any questions before we start?

### Questionnaire

1. Have you previously taken part in the Bowel Cancer Screening Programme?

☐ Yes      ☐ No      ☐ Not invited

If so, can you remember the month and year you took part.....

**Questions about bowel cancer screening (please select one option and if you are unsure, select the one you think is most appropriate)**

*If the person has not been invited for screening or previously refused, ask them to answer the questions as if they were going to be invited for screening again and what their reaction would be:*

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
2. I intend to complete the Faecal Occult Blood test (FOBt) when I receive it.					
3. I plan to complete the FOBt					

	<b>Much lower</b>	<b>Lower</b>	<b>About the same</b>	<b>Higher</b>	<b>Much higher</b>
4. Compared to other people my age, I think my risk of getting bowel cancer is					

5. For me, taking part in bowel cancer screening would be:

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree or disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
a) Beneficial					
b) Pleasant					
c) Important					

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree or disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
6. Screening is important as the NHS devotes resources to it					
7. Bowel cancer screening using the Faecal Occult Blood Test (FOBt) is organised in a way which makes it easy for me to take part					
8. It would be easy for me to read and understand the instructions about how to do the test					
9. I feel I don't know very much about bowel cancer					
10. My taking part in bowel cancer screening will benefit the NHS					

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree or disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
11. I am confident I could complete the FOB test					
12. Thinking about bowel cancer makes me feel scared					
13. It would be difficult for me to complete the FOB test because I have a mobility problem, such as arthritis					
14. I would regret not doing the FOB test if I was later diagnosed with bowel cancer					
15. Bowel cancer can be fatal					
16. I could easily fit doing the FOB test into my daily routine					
17. If bowel cancer is detected early, the chances of successful treatment are high					
18. I feel I don't know very much about the bowel cancer screening programme					
19. I would need to be at home to complete the FOB test					
20. I would feel relieved if I did the test and got a normal result					
21. There is no cure for bowel cancer					
22. I would feel embarrassed doing the FOB test					
23. It is important to me to keep healthy					
24. There are too many issues in my life for me to complete bowel cancer screening at the moment					
25. I would need to have regular bowel function in order to complete the FOBt					
26. Bowel cancer can be a hidden disease					

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree or disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
27. I would not be able to complete the FOB test as it is disgusting					
28. My religious or spiritual beliefs would not influence whether I take part in Bowel Cancer Screening.					
29. I would like to know if my GP thinks me doing the FOBt is a good idea					
30. It is important to me to look after myself for my family's sake					
31. In order to complete the FOB test, I would need put the test kit somewhere where seeing it will remind me to do it					
32. I would be worried about putting the completed FOBt kit in the post					
33. I could plan when and where I'll complete the FOB test kit					
34. I would need help from another person to complete the FOBt test					
35. Putting the samples on the card for the FOB test would be better than having to collect a sample in a pot					
36. My religious or spiritual beliefs make me want to help myself stay healthy.					
37. I might have difficulty remembering to complete the FOB test					
38. It would be inappropriate to discuss bowel cancer screening with others					
39. People close to me would approve of me doing the FOBt					
40. I would be scared of doing the FOB test in case cancer is found					
41. I'd be concerned about how to store the FOBt securely while I'm collecting samples across the 3 days					

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
42. It might be difficult to collect the sample without making a mess.					
43. Doing the FOB test could save my life					
44. It is important to me to know whether I have bowel cancer or not					
45. My religious or spiritual beliefs would make me less likely to take part in Bowel Cancer Screening.					
46. I'd be more likely to complete bowel cancer screening if I knew lots of other people had also done so.					

***Some background questions about what you know about bowel cancer (please select one option) Again there are no right or wrong answers, we are just interested in what you think***

47. How likely do you think a person aged over 60, who doesn't have any symptoms at the moment, is to die of bowel cancer?

- ☐ Very unlikely
- ☐ Unlikely
- ☐ Neither likely or unlikely
- ☐ Likely
- ☐ Very likely

48. How likely is a person aged over 60, who doesn't have any symptoms at the moment, to die of bowel cancer if they do the screening test?

- ☐ Very unlikely
- ☐ Unlikely
- ☐ Neither likely or unlikely
- ☐ Likely
- ☐ Very likely

49. What do you think an abnormal result from the bowel cancer screening test means for that person?

- ☐ The person definitely has bowel cancer
- ☐ It's highly likely that the person has bowel cancer
- ☐ The person might have bowel cancer
- ☐ It's highly unlikely that the person has bowel cancer
- ☐ The person definitely does not have bowel cancer

50. Do you think the bowel cancer screening test will find every bowel cancer?

- ☐ Yes
- ☐ No

51. Has anyone close to you (e.g. parent, sibling, partner, friend, other) presently or in the past been diagnosed with bowel cancer? **(please circle who)**

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

***Some background questions about you – we are asking all our participants but again if there is anything you would prefer not to answer then that is fine.***

52. Participant gender : ☐ Male ☐ Female

53. Can I confirm your age please?

.....

54. Does your household own or have use of a car or van?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

55. In terms of your accommodation, do you...

- ☐ Own your own home (including if with a mortgage)
- ☐ Renting from a private landlord
- ☐ Renting from Housing Association
- ☐ Renting from the council
- ☐ Living in temporary accommodation
- ☐ Other (please specify).....



56. Please indicate your highest level of formal educational qualification  
(please tick only one box)

- ☐ Postgraduate degree (e.g. PgDip, MSc, MA, MBA, PhD)
- ☐ Undergraduate degree (e.g. BSc, BA, BEng)
- ☐ Other type of higher education (e.g. HND, HNC, Nursing qualifications)
- ☐ A Levels/NVQ3
- ☐ Further education (e.g. NVQ level 2, City and Guilds, BTec diploma)
- ☐ GCSEs/O levels/CSEs
- ☐ No formal qualifications
- ☐ Other formal qualifications (please specify) .....
- ☐ Prefer not to say

57. How would you describe your ethnic group?

White

- ☐ British
- ☐ Irish
- ☐ Any other White background *please specify*.....

Mixed

- ☐ White and Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed background

Black or Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black background

Asian or Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Any other Asian background

Other ethnic groups

- ☐ Chinese
- ☐ Any other ethnic group *please specify*.....
- ☐ Prefer not to say

58. Finally, please provide your post code.....

Thank you, this is the end of the questionnaire. Do you have any further comments about the Bowel Cancer Screening Programme or the screening test?

Box to record participants' comments

Do you have any further questions? Thanks for taking part. Can I please take your address so we can send you the £20 gift voucher.

## **Appendix 6.9 Questionnaire feedback form**

### **Questionnaire feedback form**

Thank you very much for your feedback on this questionnaire that was developed from the interview work in which you took part. Before we can use this questionnaire with the public, we need to make sure it is easy to understand and there are no confusing questions.

Please would you read the questionnaire as though you were completing it for real and select the answers you would normally have chosen. Apologies if any questions feel like they are being repeated. Please circle any question questions that:

1. Do not make sense
2. Any question that sounds odd or is confusing
3. Any question that was hard to answer
4. Could have more than one meaning
5. Any question that you think we should take out.

Please write any other comments you have about the questionnaire in the box below or if it could be improved in any way. (Please continue overleaf if necessary)

**Thank you for your time, your feedback is greatly appreciated. Please would you post the questionnaire back with the feedback form in the enclosed stamped addressed envelope.**

**If you would be willing to discuss your feedback, please write your telephone number in the box below I will contact you during the week of the 16<sup>th</sup> March.**

My telephone number is:

A good date and time to call will be: